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“Then one day I broke down”.

The experience of depression and social anxiety in adolescents
with first-episode psychosis.

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Declaration of own work

I confirm that all of the work contained within this thesis is my own, except where indicated and that I have read and understood the plagiarism rules and regulations, composed and undertaken the work myself and clearly referenced/ listed all sources appropriate.

Signed

Author guidelines for submission to the chosen peer-reviewed journal, *Schizophrenia Bulletin*, can be found in Appendix 1.

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Abstract

Introduction: Young people recovering from first episode psychosis experience a high degree of emotional distress and co-morbidity. Depression and social anxiety are highly prevalent following first episode psychosis and have been associated with poorer outcome, increased risk of suicide and lower quality of life. However, there is little research examining how these emotional difficulties relate to the course of psychotic symptoms and subsequent adaptation and recovery. The primary aim of this research was to establish a grounded theory of the experience of mood and anxiety related difficulties in young people who experience a first episode psychosis. Secondly, the research aimed to establish the underlying psychological factors contributing to the relationship between psychosis and affective dysfunction.

Method: The study used a mixed-methods design with primacy given to the qualitative component (QUAL+quan). Young people (n=10) who had experienced a first-episode of psychosis were interviewed and completed measures of depression, social anxiety and recovery. Interviews were transcribed and analysed using a social constructivist version of grounded theory. Quantitative measures were integrated with the qualitative data, providing a framework for re-examining inferences made in the qualitative analysis.

Results: The overarching theme to emerge was *the experience of a developmental trajectory of psychosis*. Seven key categories were identified: *The build up; coping; breaking point; facing diagnosis; impact of illness; getting stuck and; moving on*. Isolation, low mood and anxiety were universal outcomes and appeared to be mediated by maladaptive forms of coping and mood regulation in addition to psychological appraisals and negative illness-related experiences.

Conclusions: The findings suggest that depression and social anxiety are not co-morbid features of psychosis but are intrinsically linked to the underlying processes involved in coping with and adapting to psychosis. Strengths and limitations of the research are discussed and implications for clinical practice and further research are reviewed.

1. Systematic Literature Review

Depression as a psychological reaction to psychotic illness: A systematic review of the research literature.

1.1 Abstract

Background: Depression is highly prevalent in individuals experiencing psychotic illness and is linked with poorer outcome and an increased risk of suicide. Cognitive models propose that depression may result from psychological appraisals about the impact, meaning or experience of psychosis. However, the origins of depression in psychosis remain unclear. To the author's knowledge, this is the first systematic review of the literature examining the relationship between psychological appraisals and the emergence of depression in individuals experiencing psychotic illness. **Objectives:** A systematic review of the literature was conducted to determine empirical research examining possible psychological mechanisms explaining the joint occurrence of depression and psychotic illness. **Methods:** A systematic search of the literature was performed on ASSIA, EMBASE, MEDLINE, PsychInfo, EBSCO and the Cochrane database. The search was augmented by manual searches of reference lists of retrieved articles. Study quality was graded according to the STROBE guidelines for observational studies and second rated to improve quality. **Results:** Twelve studies were identified as eligible for inclusion. Relevant information from each study was extracted and entered into a standardised table. **Conclusions:** Broadly speaking, studies fell into one of two conceptual frameworks: a) articles conceptualising depression in relation to appraisals about the meaning and/ or life impact of the diagnosis/ illness; b) those conceptualising depression in relation to appraisals about aspects of the illness itself. A number of methodological weaknesses in the existing literature were identified. Areas for future investigation may include developing a greater understanding of mediating variables and a focus on the efficacy of interventions designed to facilitate reappraisal of negative beliefs about the impact or experience of psychotic illness.

Keywords: Psychosis; schizophrenia; depression; negative symptoms; low mood.

1.2 Introduction

Schizophrenia is a chronic and often disabling mental illness characterised by symptoms including hallucinations, delusions, disorganised communication and blunted affect. Research examining the global prevalence of schizophrenia suggests a life time prevalence of 4.6 per 1000 (Saha *et al.*, 2005), whereas the lifetime prevalence of psychotic disorders more broadly (including schizoaffective disorder, schizophreniform disorder and delusional disorder) exceeds 3 per cent (Perela *et al.*, 2007). 80 per cent of first episodes of psychosis emerge between the age of sixteen and thirty (Lester *et al.*, 2009) and a wealth of literature indicates that schizophrenia is an illness with relatively poor emotional, social and occupational outcome (Jobe & Harrow, 2005). Risk of suicide is also high in this group, with 40 per cent reporting suicidal ideation, 23 per cent making at least one suicide attempt (Fenton *et al.*, 1997) and an estimated 10 per cent of people suffering with schizophrenia completing suicide (Caldwell *et al.*, 1992).

Schizophrenia is a clinically heterogenous disorder. Constellations of symptoms vary widely between individuals and can change radically over time. This picture is complicated further by the psychiatric comorbidity which is so common in schizophrenia. In particular, depression, anxiety and substance abuse are prevalent and there is significant interplay between these disorders over the longitudinal course of the illness (Buckley *et al.*, 2008). Clearly, this has implications for understanding the aetiology and treatment of schizophrenia.

Whilst depressed mood has long been acknowledged in the literature on schizophrenia, according to Birchwood (2005, p. 202) 'Emotional dysfunction and schizophrenia have long been uncomfortable bedfellows'. In 1908, Bleuler published observations of depressive symptomatology in patients with schizophrenia, proposing that in some cases these symptoms appear to be triggered by the disease process itself and in others, they take the role of secondary symptoms. Despite a lengthy history of debate, the presence of depression in schizophrenia-spectrum disorders remains contentious. This is in part, due to the fact that historically, in hierarchical diagnostic models positive and first rank symptoms of schizophrenia have 'trumped' affective symptoms and as such, little emphasis was placed on the depressive symptoms so commonly experienced. In addition, the overlap between negative and depressive symptoms has clouded the picture further. However, whilst a phenomenological overlap may occur between the two, affecting assessment of depressive

symptoms (Siris *et al.*, 1988), the predominant view is that negative symptoms and depression are distinct entities (Chemerinski *et al.*, 2008). Indeed, more recently, a move towards developing a more comprehensive understanding of schizophrenia-spectrum disorders has led to a revival in interest in the role of affect in the development and maintenance of psychotic illness.

Prevalence figures for depression in schizophrenia vary widely between studies. According to a review by Siris & Bench (2003), prevalence rates range from 6 to 75 per cent with a modal value of 25 per cent, dependent on the phase of illness, treatment setting and the definition of depression. However, regardless of methodological and population differences, the majority of studies indicate that most people (around 80 per cent) experiencing first episode psychosis will, at some stage during the course of their illness, experience a clinically significant depressive disorder (Upthegrove *et al.*, 2010). This recognition has led to the creation of the syndromal definition 'post psychotic depressive disorder of schizophrenia', which in earlier times was used as a description of a dysphoric state immediately following a psychotic episode, but is now used to describe depression that occurs at any time following a psychotic episode in schizophrenia, even if this follows a lengthy interval (Siris, 2000).

Although at one time, concurrent depressive symptoms were thought to be associated with favourable outcome, more recent research indicates otherwise. Co-morbid mood disturbance has repeatedly been associated with worse outcome, including impaired functioning (Roy *et al.*, 1983), higher rates of relapse and rehospitalisation (Johnson, 1988; an der Heiden *et al.*, 2005), greater unemployment (Sands & Harrow, 1999), greater substance misuse and poorer family relationships, mental functioning and quality of life (Conley *et al.*, 2007). In terms of recovery, severity of depressive symptoms have been shown to be strongly and negatively correlated to all components of recovery and serve as a poor prognostic indicator of reintegration into the community (Resnick *et al.*, 2004). Concurrent depression also carries increased risk of suicide. Clinically, the most common correlate of suicide in schizophrenia is depressive symptoms, which are frequently associated with feelings of hopelessness, isolation and demoralisation (Siris, 2001). The prevalence of suicidal behaviour during the first years after the start of treatment has been shown to rise in parallel with the severity of depressive symptomatology (Gonzalez-Pinto *et al.*, 2007). Undoubtedly, the recognition and understanding of depression in psychotic illness is crucial if we are to improve the long term outcome and quality of life for this population and make an impact on suicide rates.

Several hypotheses have been proposed to explain the occurrence and aetiology of depressive symptomatology in psychotic illness. Early research observed higher depression scores in patients treated with neuroleptic drugs than those treated without them, leading to suggestions that depression was a pharmacogenic response to antipsychotic medications used to treat schizophrenia (Bandelow *et al.*, 1992). Another view, based on research into the separability of schizophrenia and affective disorders by their symptoms and course, proposes that depressive symptoms do not represent co-morbidity but are an integral part of psychosis. Hafner (2010) found that the symptom most frequently marking the onset of both schizophrenia and depression was depressed mood and it was only upon the emergence of positive symptoms that the disorders became separable by international classification systems. Evidence that depressive symptoms increase during psychotic exacerbations has also been used in support of this perspective (Green *et al.*, 1990).

Despite the fact that the relationship between depressive symptomatology and psychotic illness has been the focus of an expanding body of research, this relationship remains far from conclusive and for several reasons, the literature is seriously lacking in clarity. The research has varied widely in its methodology, in the populations and time periods studied and measures used. According to Mulholland & Cooper (2000) the literature is further confounded by the ‘multiplicity of terms’ (p. 174) used to define depression. Furthermore, Siris (2000) points out that the literature in this area is often imprecise as to whether the ‘affect’ of depression, the symptom, or the syndrome of depression is being considered and these different meanings have too frequently been used interchangeably and loosely.

Whilst a comprehensive review of all research investigating the aetiology of depression in psychotic illness is beyond the scope of this paper, the current review aims to add some clarity to one specific area of the literature. A systematic review of the literature was conducted to determine empirical research exploring possible psychological mechanisms explaining the joint occurrence of depression and psychotic illness.

1.3 Method

1.3.1 Search strategy

A literature search using the following databases was carried out in March 2011: ASSIA (1980 to March 2011), EMBASE (1980 to March 2011), MEDLINE (1980 to March 2011), Psychinfo (1980 to March 2011), and EBSCO (1980 to March 2011). The search terminology

used was: (psychosis OR schizophrenia) AND (depression OR negative symptoms OR low mood). The search was limited to journals in the English language.

1.3.2. Inclusion criteria

Articles clearly specifying that depression has resulted as a result of psychological appraisal about the impact, meaning or experience of psychosis; published in a peer-reviewed journal article; include participants who had a primary diagnosis of schizophrenia or related psychosis.

1.3.3. Exclusion criteria

Articles which did not clearly assess depressive symptomatology.

1.3.4. Search results

The search strategy initially identified a total 3456 publications (862 from ASSIA, 919 from EMBASE, 581 from MEDLINE, 734 from PsychInfo and 360 from EBSCO). This was reduced to 2864 after removing duplicates. These searches, along with a search of the Cochrane library of systematic reviews using the search terms ‘schizophrenia’ and ‘depression’, revealed that no similar systematic reviews had been published under these terms. The first step of screening the titles of these publications resulted in the identification of 350 articles (60 from ASSIA, 97 from EMBASE, 100 from MEDLINE, 67 from PsychInfo and 26 from EBSCO). The second step of manually reviewing the abstracts of these papers resulted in 59 articles. In the case of uncertainty over the inclusion of a paper, the methodology and results section were also reviewed. Manual searching of the reference lists of relevant publications revealed a further 20 publications for screening. The final step of retrieving and reviewing these 79 papers in full, identified a total of 12 publications which fulfilled the inclusion criteria for review.

1.3.5 Critical appraisal

Due to the small number of publications fulfilling inclusion criteria, assessment of study quality was not included as an inclusion criterion. However, the quality of all papers meeting inclusion criteria was assessed. All articles meeting inclusion criteria were non-experimental (observational) studies. An observational study can be defined as ‘an etiologic or effectiveness study using data from an existing database, a cross-sectional study, a case

series, a case-control design or a cohort design' (Stroup *et al.*, 2000 p. 2008). Whilst the use of critical appraisal tools designed for experimental research is common practice in the appraisal of non-experimental research, this is often not appropriate. Indeed, assessment of the quality of observational studies is often more difficult than assessment of the quality of randomised controlled trials and other experimental studies. In particular, due consideration needs to be given to methodological issues particular to observational designs, e.g. confounding, inherent biases, differences in study designs (Sanderson, 2007).

Study quality was appraised according to the STROBE guidelines developed by van Elm *et al.*, (2008). Whilst these guidelines were developed for the reporting of observational research, as Sanderson *et al.*, (2007) point out, considerably less attention has been paid to the development of quality checklists for this area of application. The STROBE guidelines were developed during a two-day workshop attended by twenty-three individuals, who included methodologists, statisticians, epidemiologists and practitioners. Relevant empirical evidence and methodological work was reviewed and consecutive draft guidelines were subject to an extensive iterative process of consultation (Appendix 2). Due to this comprehensive process of development and the fact that the guidelines can apply to both cohort and cross-sectional studies, for the purpose of this review, these guidelines were deemed to be suitable for the assessment of study quality. As a quality control measure, a random selection of six of the included articles were second rated by a consultant clinical psychologist working with the author.

1.4 Results

1.4.1 Overview of reviewed studies

Table 1 provides an overview of each article, presented chronologically. Sample size ranged from n=21 to n=257, with three studies recruiting fewer than 30 participants experiencing psychosis. The mean number of participants per study was 97. The majority of studies employed a cross-sectional design (n=7) and used statistics of association (e.g. correlation or regression analysis) to examine the relationship between appraisals about psychosis and depression.

Table 1: Summary of studies investigating the relationship between psychological attributions about psychosis and depression.

<i>Reference (date ordered)</i>	<i>Design</i>	<i>Number of participants</i>	<i>Mean age/ (age range) where reported</i>	<i>Diagnosis of participants</i>	<i>Measure(s) of depression*</i>	<i>Key findings</i>	<i>Limitations</i>
Birchwood <i>et al.</i> , (1993)	Cross sectional	84	42.1 years	Schizophrenia; bipolar disorder	BDI	Entrapment in illness was the most powerful discriminator between depressed and non depressed participants. Depressed participants had lower expectations and expressed a more external locus of control. Number of admissions and unemployment predicted depression.	Investigates 'secondary depression' in a sample which includes bi-polar patients, raising conceptual difficulties (i.e. 'intrinsic' vs. 'reactive' depression). Does not describe any efforts to address potential bias. No control group.
Soppitt & Birchwood (1997)	Cross sectional	21	43 (20-72)	Schizophrenia	BDI	Participants who experienced derogatory voice content were significantly more depressed than those whose voice content was benevolent. Strong positive correlations between depression and intrusiveness and volume of voices.	Small sample size limits external validity. Only moderate agreement between raters (kappa +0.6) on derogatory vs non derogatory voice content limits internal validity. No control group.
Rooke & Birchwood (1998)	Prospective cohort study	47	42.1 years	Schizophrenia	BDI	Appraisal of entrapment by psychosis was the principle discriminator between depressed and non-depressed participants. Perceived loss of autonomy and social role correlated with depression.	Small sample size limits external validity. No control group. Does not describe any efforts to address potential bias.

Table 1 (continued): Summary of studies investigating the relationship between psychological attributions about psychosis and depression.

<i>Reference (date ordered)</i>	<i>Design</i>	<i>Number of participants</i>	<i>Mean age/ (age range) where reported</i>	<i>Diagnosis of participants</i>	<i>Measure(s) of depression*</i>	<i>Key findings</i>	<i>Limitations</i>
Iqbal <i>et al.</i> , (2000)	Prospective cohort study	105	(18-65)	Schizophrenia or related disorder (F20, F22, F23)	BDI; CDSS; DEQ	Participants who appraised their psychosis as embodying greater loss, shame and entrapment were significantly more likely to develop depression.	Characteristics of sample not described, drop-outs (22%) differed in age and age at first episode, limiting generalisability. Small numbers in relapsing group (n=11) limit power of between group analyses. No control group.
Freeman <i>et al.</i> , (2001)	Cross sectional	25	37 (22-60)	Schizophrenia; schizoaffective disorder; delusional disorder.	BDI	Lower feelings of control over the perceived persecutory situation and low perceived ability to cope with it are associated with higher levels of depression. Higher evaluation of power of the persecutor associated with depression.	Small sample size limits external validity and prevents examination of mediating factors. Reliance on numerous correlations risk occurrence of Type I errors. No control group.
Birchwood <i>et al.</i> , (2004)	Cross sectional	125	33.7 years	Schizophrenia; paranoid psychosis; schizophreniform disorder	BDI	Participants who attributed greater power and rank to their dominant voice than themselves were significantly more depressed than those who did not.	Participants rated only their most dominant voice, introducing bias in favour of a greater power differential. Does not report psychometric properties of all measures. No control group.

Table 1 (continued): Summary of studies investigating the relationship between psychological attributions about psychosis and depression.

<i>Reference (date ordered)</i>	<i>Design</i>	<i>Number of participants</i>	<i>Mean age/ (age range) where reported</i>	<i>Diagnosis of participants</i>	<i>Measure(s) of depression*</i>	<i>Key findings</i>	<i>Limitations</i>
Drake <i>et al.</i> , (2004)	Prospective cohort study	257	Not reported	Schizophrenia; schizoaffective disorder; schizophreniform disorder; delusional disorder; psychosis (NOS)	'Depression factor' derived from four items from the PANSS (anxiety; depression; guilt; avolition)	Depression predicted by greater insight (particularly at baseline) with the likely direction of causation being that increasing insight leads to depression. Paranoia strongly associated with depression with the likely direction of causation that paranoia causes depression. Longer duration of untreated psychosis and substance abuse at baseline predict depression.	'Depression factor' derived from PANSS – limits internal validity. 17% of sample had daily drug/ alcohol (ab)use – possibly confounding results. No control group.
Lobban <i>et al.</i> , (2004)	Prospective cohort study	124	38.8 years	Schizophrenia; schizoaffective disorder; psychosis; delusional disorder.	HADS	Beliefs about greater negative consequences of illness strongly predicted depression in both cross sectional and longitudinal analyses.	No control group. Amounts of variance accounted for by beliefs were small (2% for depression). Relatively short (6 mnth) longitudinal analysis. Does not report psychometric properties of all measures, limiting internal validity.

Table 1 (continued): Summary of studies investigating the relationship between psychological attributions about psychosis and depression.

<i>Reference (date ordered)</i>	<i>Design</i>	<i>Number of participants</i>	<i>Mean age/ (age range) where reported</i>	<i>Diagnosis of participants</i>	<i>Measure(s) of depression*</i>	<i>Key findings</i>	<i>Limitations</i>
Birchwood <i>et al.</i> , (2005)	Cross sectional	26	Not reported	First episode of psychosis.	CDSS	Depression is significantly correlated with perception of the degree of threat of persecutors and the perceived ability to escape/ control the threat. Participants who appraised their psychosis as embodying greater 'loss', 'shame' and ' entrapment' were significantly more likely to experience depression.	Preliminary study with small sample size and characteristics of participants not reported therefore limited generalisability. No control group.
Crumlish <i>et al.</i> , (2005)	Prospective cohort study	101	(13-58)	Schizophrenia; schizophreniform disorder	PANSS (depression subscale)	Depression positively associated with more complete insight (both self and observer rated). Recognition of mental illness at six months post presentation predicted depression and attempted suicide at four years.	Birchwood Insight Scale (BIS) only introduced mid way though study. Small final sample size due to missing data – may be underpowered. Limited assessment of depression. No control group.
Watson <i>et al.</i> , (2006)	Cross sectional	100	(18-65)	Non affective psychotic disorder	BDI-II	Negative illness perceptions (e.g. high level of perceived consequences of illness; low level of control) were significantly associated with depression and emotional dysfunction more generally (anxiety & low self esteem).	No control group. Does not report psychometric properties of all measures, limiting internal validity. Sample may not be representative of population with psychosis.

Table 1 (continued): Summary of studies investigating the relationship between psychological attributions about psychosis and depression.

<i>Reference (date ordered)</i>	<i>Design</i>	<i>Number of participants</i>	<i>Mean age/ (age range) where reported</i>	<i>Diagnosis of participants</i>	<i>Measure(s) of depression*</i>	<i>Key findings</i>	<i>Limitations</i>
Karatzias <i>et al.</i> , (2007)	Cross sectional	138	36.5 years	Schizophrenia; schizoaffective disorder; schizophreniform disorder; delusional disorder; psychosis (NOS)	SCID	<p>Participants with a co-morbid affective disorder (depression and/ or anxiety) were significantly more likely to have negative appraisals of entrapment in psychosis.</p> <p>Affective co-morbidity is significantly associated with greater self blame, shame and humiliation and lower functioning.</p>	<p>No control group. Did not differentiate between depression and anxiety in 'co-morbid affective disorder' group. No follow up. Use of 'relapse prone' patients, may affect external validity.</p>

* BDI/ BDI-II Beck Depression Inventory; CDSS Calgary Depression in Schizophrenia Scale; DEQ Depressive Experiences questionnaire; HADS Hospital anxiety and depression scale; PANSS Positive and Negative Syndrome Scale; SCID Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

Depression was measured using a variety of questionnaires and interview schedules. In over half (n=7) depression was assessed using the Beck Depression Inventory (BDI, Beck *et al.*, 1961) or second edition (BDI-II, Beck *et al.*, 1996). Two used the Calgary Depression Scale for Schizophrenia (CDSS, Addington *et al.*, 1993), one used the HADS (Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983), one used the depression subscale of the PANSS (Positive and Negative Syndrome Scale, Kay *et al.*, 1987), one used the SCID (Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, Segal *et al.*, 1994) and one study used a 'depression factor', derived from four items (anxiety, depression, guilt and avolition) from the PANSS.

1.4.2. Conceptualisations of depression in psychotic illness

Whilst all of the included articles conceptualise depression as a psychological reaction to the psychosis, within this overarching concept, they can be divided into two categories. Firstly, those which conceptualise depression as arising due to appraisals about the meaning and significance of the psychotic illness and/ or presumed diagnosis. Secondly, those which suggest that depression arises due to appraisals about aspects of the psychotic illness itself, i.e. in relation to voices, paranoia and the content of delusions. For clarity these will be reviewed under two separate headings.

1.4.2.1. Depression arising as a consequence of negative appraisals of the meaning and significance of the illness and/ or diagnosis.

Within this category there are eight non-experimental cohort studies. Five of these had a prospective, repeated measures design and three had a cross-sectional design. Articles are presented in chronological order.

Birchwood *et al.*, (1993) were the first to examine the relationship between personal reactions to psychotic illness and depression. They explored the hypothesis that depression in chronic schizophrenia is, in part, a psychological response to an apparently uncontrollable life event, i.e. the psychotic illness and its resulting disabilities. Their sample consisted of 84 patients (49 diagnosed with schizophrenia, 35 with bi-polar disorder), all receiving long term maintenance therapy. The cross-sectional prevalence for depression in participants with schizophrenia was 29 per cent, and for those with bi-polar disorder, 11 per cent. In keeping with their hypothesis, analyses revealed that depressed participants demonstrated significant differences in their beliefs about their illness, including their future expectations, and

internalised stigma. Belief in control over illness appeared to be the principle contributor to depression and demoralisation, powerfully discriminating depressed from non-depressed psychotic patients. Number of hospital admissions and unemployment also emerged as predictor variables for depression.

These findings are limited by some methodological limitations. Firstly, the study investigated 'secondary depression', yet the sample included patients with a diagnosis of bi-polar disorder. The authors acknowledge that this presents a conceptual difficulty, in that in an observational study such as this; it is not possible to distinguish between depression which results as a psychological reaction to a diagnosis and/ or experience of the illness, from depression which is intrinsic to the illness itself. In assessing beliefs about voices, the study relied on the use of a new questionnaire which had not been validated and may have affected the integrity of the findings. In addition, the correlation design prevents any inference about causality of psychological attributions.

Rooke & Birchwood (1998) extended this study by following up the original sample of 49 patients with schizophrenia 2.5 years after original assessment. Two had died of natural causes and all remaining participants agreed to take part in the study. The authors employed the same measures of symptoms and appraisals of illness. Compared to 28 per cent prevalence of depression at first assessment, 17 per cent of the sample was depressed at follow-up. Multivariate analyses revealed significant differences between depressed and non-depressed patients. Specifically, depressed patients appraised themselves as more entrapped by their illness, believed they had lost more in terms of autonomy and social role and were more likely to appraise the locus of their illness within their personality than in biomedical terms. In addition, a higher number of compulsory admissions and a greater drop in employment were independently linked to depression. A discriminant function analysis indicated that belief in entrapment at inclusion and follow-up was the principle discriminator between depressed and non-depressed patients. Methodologically, use of a prospective design adds more weight to these findings than the original cross-sectional design. However, the relatively small sample size limits external generalisability and has implications in terms of the statistical analyses undertaken, in particular the discriminant function which lacked statistical power to detect subtle differences and may therefore affect the conclusions drawn. Lastly, the authors acknowledge that life events independent of the psychosis were not measured or controlled for and this may have biased findings.

Iqbal *et al.*, (2000) used a prospective, repeated measures design in order to investigate the appraisal of self and psychotic illness and their link with the later emergence of post-psychotic depression. Participants (n=105) with a diagnosis of schizophrenia were followed up over a period of twelve months (post acute episode) and assessed on measures of depression, insight, appraisals of psychosis, working self concept and cognitive vulnerability. Before developing post-psychotic depression, these patients were significantly more likely than patients who did not develop depression, to attribute the course of psychosis to the self, rather than to an externalised illness, to perceive greater loss of autonomy and valued role and to perceive themselves to be more entrapped and humiliated by their psychotic illness. Participants who went on to develop post-psychotic depression had significantly lower self esteem both before and during the depressive episode. The authors conclude that ‘the mechanism underlying post-psychotic depression was dependent on the individual’s own experience of psychosis and how he/she appraises its implications for the self’ (p. 526). Whilst this study was well designed and reported, its findings are limited by the large drop-out rate (22.8 per cent) during follow-up. Drop-outs were found to differ significantly from the main sample and were older both chronologically and in terms of age at first episode of psychosis, which may have introduced a bias. Other than age range, characteristics of the sample were not reported. Small numbers (n=11) in the relapsing group mean that between-group analyses lacked power. Furthermore, the research did not assess pre-morbid functioning or depressive history, limiting the strength of these findings.

Lobban *et al.*, (2004) report a prospective cohort study in which they assessed 124 participants with a diagnosis of schizophrenia on measures of symptom severity, beliefs about their mental illness, coping and appraisal of outcome. Measures were repeated at six months. Using multivariate analyses and controlling for symptom severity, beliefs about mental health were found to significantly predict outcome. In particular, beliefs about greater negative consequences were the strongest and most consistent predictors of depression in both cross-sectional and longitudinal analyses. Depression at six months was also predicted by greater symptom severity and a more chronic perception of the timeline of the illness at first assessment. The authors acknowledge the relatively short follow up and made efforts to control for potential sources of bias, e.g. controlling for unequal group size and assessing inter rater reliability. Drop-outs (17.7 per cent) were demonstrated not to differ significantly from those who were retained on any of the variables assessed. However, inferences about the generalisability of the findings cannot be made due to the lack of reporting of some

characteristics of the sample population (e.g. gender or ethnicity). In addition, quality of life in this study was assessed using a measure for which no psychometric properties were reported, highlighting that the concept being measured may not have been robust.

Drake *et al.*, (2004) investigated how insight, paranoia and depression in psychosis evolve in relation to each other, during and in the eighteen months following onset. Serial assessments of depression, insight, paranoia and self esteem were conducted with a sample of 257 participants diagnosed with first-episode non-affective psychosis. Measures were analysed using structural equation modelling, which allowed them to examine the direction of relationships over time after controlling for confounds. Good insight was strongly associated with depression, with the likely direction of causation being that increasing insight leads to depression. Paranoia was also strongly related to depression and appeared to cause it. Baseline variables of longer duration of untreated psychosis and substance abuse also predicted depression at 18 months. Methodologically, this study has many strengths, including a large representative sample and statistical analyses which adjusted for confounds. However, rather than utilising a well validated measure of depression in psychosis, depression was assessed by means of a 'depression factor', derived from using four factors on the PANSS, which may have affected the overall reliability of assessment this variable. Their sample also included 17 per cent who had daily drug or alcohol (ab)use. Whilst this may be reflective of the population as a whole, it is possible that this may have impacted participants' insight, possibly introducing a bias.

Crumlish *et al.*, (2005) carried out a prospective cohort study with 101 participants with first episode psychosis. The authors mapped the development of insight in the 4 years after onset of psychosis and determined the effects of evolving insight on depression and the likelihood of attempted suicide. Regression analyses allowed for potentially confounding determinants of insight such as duration of untreated psychosis, positive and negative symptoms and education. The study found that 3 per cent of participants had full insight at presentation. This increased to 37 per cent at four years. Depression was positively associated with more complete insight (both self and observer rated) and at six month assessment greater recognition of mental illness predicted higher depression scores at four years and higher likelihood of suicide attempts. This was a well designed and reported study, drawn from a large, epidemiologically complete catchment area, which used reliable measures and reported attempts to control for confounding, e.g. employing blind rating and establishing that those

participants without complete data were indistinguishable at first presentation on all relevant demographic and illness variables. However, one major limitation relates to the fact that the insight measure was only introduced fourteen months into recruitment and therefore 26 participants were not assessed with this measure at presentation. Missing data as a result of this and attrition mean that the sample size was modest and therefore may have been underpowered to detect some associations. In addition, the group included in the regression model examining the relationship between insight at presentation and four year outcome was shown to differ significantly from the group excluded from the analysis, in that they were more likely to have a lifetime history of drug abuse or dependence, potentially biasing findings.

Watson, *et al.*, (2006) conducted a cross-sectional study with 100 patients with a diagnosis of non-affective psychosis. Participants were assessed within 3 months of relapse on measures of insight, self reported illness perceptions, medication adherence and self esteem. The authors hypothesised that apprehensions of a longer timeline of illness, worse perceived consequences, a low sense of control and a heightened perception of symptoms would be associated with emotional dysfunction (depression and anxiety). Multiple regression analyses revealed that illness perceptions about psychosis explain a substantial proportion of the variance in depression (46 per cent), anxiety (36 per cent) and self esteem (34 per cent), supporting their hypotheses. However, in terms of generalisability of the sample, participants had been recruited into an intervention trial and therefore may not be representative of the psychotic population as a whole. Additionally, this study relied in part on non-validated Likert scales, which may affect the integrity of the reported findings.

More recently, Karatzias *et al.*, (2007) investigated the hypothesis that controlling for the severity of positive and negative symptoms, greater negative beliefs about the psychotic illness and lower self esteem will be significantly associated with the presence of anxiety or affective co-morbidity. In a cross-sectional research study, a sample of 138 individuals with schizophrenia or a related psychotic disorder were assessed for psychotic and affective symptoms, beliefs about voices, self esteem and general functioning. Of the total sample, 44.9 per cent had a co-morbid anxiety or affective disorder, the presence of which was associated with significantly more negative symptoms, greater general psychopathology (as measures by the PANSS) and lower functioning. Multiple logistic regression analyses showed that participants with a co-morbid anxiety or affective disorder had significantly

lower levels of functioning, more negative appraisals of entrapment in psychosis and lower levels of self esteem. This lead the authors to suggest that negative beliefs about psychotic experiences and self esteem may be linked to the development and maintenance of anxiety and affective disorders. Unfortunately, the sequence of onset of co-morbid disorder(s) was not documented, leaving the possibility that the co-morbid conditions may have preceded the diagnosis of psychotic illness. A further limitation relates to the fact that the study did not differentiate between types of co-morbid disorder, although these groups may differ from each other in terms of clinical correlates. Participants were recruited from a sample which was part of a larger research trial investigating the efficacy of cognitive behavioural therapy for psychosis and as such, may not be generalisable to the wider population.

1.4.2.2. Depression arising due to appraisals about symptoms of the psychotic illness itself

Within this category there are four non-experimental cohort studies, all with a cross-sectional design.

Appraisals relating to voice hearing

Two studies investigated associations between aspects of auditory hallucinations and depression. Soppitt & Birchwood (1997) assessed participants with a diagnosis of schizophrenia for depression, voice topography and beliefs about voices. They classified the nature of the voice content as derogatory or non-derogatory. They found that participants were significantly more likely to be depressed if they experienced derogatory voice content. Depression was correlated with the presence of malevolent hallucinations as well as voice intrusiveness. However, the small sample size ($n=26$) limits the external validity of this study. There was also moderate disagreement between the author and a blind rater who coded the voice content as derogatory ($\kappa=0.6$), limiting the internal validity. In addition, whilst two of the four measures used demonstrate good psychometric properties, the study also relied on the use of two non-standardised measures to assess voice topography and participants' perceptions of the voice.

Birchwood *et al.*, (2004) extended these findings, hypothesising that patients who perceive themselves to possess low social power and status will also perceive themselves to be subordinate to their dominant voice and will attribute more power to the voice. The findings supported this hypothesis. Covariance structural equation modelling was used to test

‘goodness of fit’ for three models in addition to the null model (i.e. no relationship between variables: Firstly, depression is primary and leads to the appraisal of social rank, voice power and distress. Secondly, greater voice activity (volume, frequency) in addition to the presence of delusions about voices leads to depression and the appraisal of voices’ power. Thirdly, social rank and power lead to the appraisal of voice power, distress and depression (the hypothesised model). The null model and the first and second models were rejected. The hypothesised model failed to be rejected and provided the best fit with the data. Birchwood *et al.*, (2004) conclude that the role relationships that a person has with others are mirrored in their internal experiences with voices and it is the degree of powerlessness that a person feels in relation to the dominant voice that is closely allied with depression. In addition the findings indicated that as well as being experienced as dominant, malevolent voices are also experienced as shaming and attacking which may lead a person to be ‘harassed’ into depression (p. 1577).

Of the two studies described here, the latter is more methodologically sound, mainly owing to a larger sample size (n=125) which was drawn from a large urban population and was representative of the population of individuals with psychotic illness. However, the researchers acknowledge the possible introduction of a bias in favour of greater power differential because in the case of participants reporting more than one voice, they were asked to identify the more dominant one for assessment. In addition, one of the measures used to assess social comparison was developed for use with depressed populations and had not been validated with a psychotic population and the authors used a non validated Likert scale to assess perceived distress in relation to the voices. Lastly, whilst the sample size was sufficient to reject two models, it was not large enough to examine the hypothesised model in more detail, i.e. at an item level analysis.

Appraisals relating to delusional beliefs/ content.

Two studies investigated the relationship between delusional beliefs and depression. Both had cross-sectional designs. Freeman *et al.*, (2001) sought to develop the cognitive understanding of persecutory delusions. They hypothesised that safety behaviours contribute to the persistence of persecutory delusions by preventing disconfirmation and that emotional distress would be associated with aspects of the content of delusions. A sample of 25 individuals who were experiencing persecutory delusions was assessed for the presence of safety behaviours, delusional content and depression and anxiety. The vast majority of the

sample (n=21) were experiencing clinically significant levels of depression and all participants had reported using safety behaviours (typically avoidance) in relation to delusions during the past month. In keeping with the hypothesis, appraisals regarding aspects of delusions (higher ratings of power of persecutor and lower sense of control over persecutory situation) were associated with increased depression. In addition, individuals who believed that the anticipated harm was deserved were significantly more depressed and had significantly lower self esteem than those who did not. Unfortunately, the sample size presents a significant methodological weakness and prevented any further examination of whether these associations were mediated by other factors. The heavy reliance on correlations risks the occurrence of Type I errors and both safety behaviours and perceived threat from persecutors were assessed by way of new, non-validated scales. Furthermore, the researchers utilised only specific subscales of validated measures used to assess anxiety, affecting the overall reliability of the measure.

Birchwood *et al.*, (2005) reported on a preliminary study with individuals experiencing acute psychosis which investigated the relationship between depression, appraisals about voices and the impact of the psychosis on the person's life. Initial results showed that 66 per cent of those assessed were significantly depressed, according to a well validated measure of depression in schizophrenia (CDSS, Addington *et al.*, 1993). Results indicated significant correlations between depression and the perception of the degree of threat attributed to the persecutors and the perceived ability to escape from and control this threat. This was independent of positive symptoms of psychosis. Secondly, patients who appraised their psychosis as encompassing greater 'loss', 'shame' and 'entrapment' reported significantly higher levels of depression, independent of acute symptomatology. This study was presented as part of a special edition which also summarised evidence from two other studies featured in this review (Iqbal *et al.*, 2000; Birchwood *et al.*, 2004) therefore, only limited details of the design and methodology were reported. In particular, characteristics of the study population were not reported and the authors did not acknowledge any limitations or potential confounding factors. The external validity of this study is poor due to these factors in addition to the small sample size (n=26).

1.5. Discussion

1.5.1. Methodological considerations of the studies

No previous systematic reviews, meta-analyses or randomised control trials (RCT's) had been conducted in this area. In addition to the aforementioned methodological weaknesses specific to each of the studies reviewed, the literature as a whole has a number of limitations. Firstly, all studies were observational cohort studies, none of which had a control group. Clearly, allocation of participants with psychotic illness to a control group and/ or experimental manipulation of variables which may affect their mood or functioning would be unethical. However, observational studies are generally regarded as inferior to RCT's and case control studies in terms of reliability (Petticrew & Roberts, 2006). Taken as a group then, the validity of these studies may be threatened because of their vulnerability to selection bias.

Most studies reported were relatively small, with three recruiting fewer than 30 participants and only seven including more than 100 participants, reducing the potency of any conclusions drawn from these findings. Furthermore, research has indicated that observational studies tend to produce larger estimates of effect than studies with experimental designs (Khan *et al.*, 2003). Seven of these studies relied on cross-sectional designs; hence the direction of causality in these studies remains unclear. Indeed, there remains the possibility that the cognitive vulnerability factors identified in many of these studies are an epiphenomena of past depressive episodes and may not be causal (Iqbal *et al.*, 2000).

Only one of the studies (Crumlish *et al.*, 2005) included young people in their sample (age range 13-58), although they did not differentiate between adolescents and adults in their analyses, limiting observation of possible developmental factors. Another noteworthy limitation is that although all of these studies assessed depression, not all of them reported whether negative psychotic symptoms were controlled for. For example, Karatzias *et al.*, (2007) reported an unexpected finding that affective co-morbidity was significantly associated with higher levels of negative symptoms and queried whether this resulted due to an issue with measurement of negative symptomatology or the overlap between negative and depressive symptoms. Lastly, all of the studies reviewed were undertaken in Western societies. It may be that cultural norms influence these types of psychological appraisals and that these findings cannot be generalised more widely.

1.5.2. Synthesis of research findings

Bearing in mind the limitations outlined above, the findings from this systematic review suggest that psychological appraisals about the impact, meaning or experience of psychosis appear to have a role in the onset and maintenance of depression in individuals experiencing psychotic illness. Conceptually, there are two streams in terms of the current literature. Eight of the reviewed studies explored the relationship between depression and appraisals about the meaning and significance of the illness. In particular, the concept of ‘entrapment’ in illness and/ or perceived loss of control emerged as a powerful discriminator between depressed and non-depressed participants in six studies (Karatzias *et al.*, 2007; Watson *et al.*, 2006; Iqbal *et al.*, 2006; Rooke & Birchwood, 1998; Birchwood *et al.*, 1993 and; Birchwood *et al.*, 2005). Perceived loss of autonomy and valued role was associated with higher levels of depressive symptomatology in three studies (Birchwood *et al.*, 1993; Rooke & Birchwood, 1998 and; Iqbal *et al.*, 2006) as were beliefs about greater negative future consequences (Lobban *et al.*, 2004).

The relationship between insight (including recognition of mental illness, recognition of need for treatment and the ability to re-label psychotic symptoms) was investigated in two studies. Good insight was strongly associated with depression with the likely direction being that increasing insight leads to depression (Drake *et al.*, 2004). In keeping with these findings, individuals who had higher insight six months after the onset of psychosis were significantly more likely to experience depression at four years and were more likely than those with lower insight at six months to have attempted suicide (Crumlish *et al.*, 2005).

Four of the reviewed studies explored the relationship between depression and appraisals relating to the experience of psychotic symptomatology. Two studies investigated appraisals about voice hearing. Individuals who experienced derogatory auditory hallucinations were significantly more at risk of developing depression (Soppitt & Birchwood, 1997). Those who felt more powerless in relation to their dominant voice were more likely to experience depression. This sense of subordination appeared to mirror their experiences with others around them (Birchwood *et al.*, 2004).

The relationship between depression and appraisals relating to delusions was investigated in two studies. Individuals who attribute higher levels of power to their perceived persecutor are significantly more likely to be depressed (Freeman *et al.*, 2001). In addition, individuals who perceive themselves to have less ability to escape from the persecutory situation and who feel

a lower sense of control over the threat are more likely to experience depression (Birchwood *et al.*, 2005).

1.5.3. Implications for clinical practice

In keeping with previous research (e.g. Buckley *et al.*, 2008) depression was found to be prevalent in all of the reviewed studies. In light of the link between depression and suicide in this group as well as the outcome literature reporting poorer outcome in individuals experiencing co-morbid psychosis and depression (e.g. Resnick *et al.*, 2004), a priority for clinicians working with this group should be the assessment of depression and suicidal ideation at each stage of the illness. Assessment needs to link emotional distress with delusional content and a person's appraisals about both the symptoms and meaning of psychosis. Indeed, it could be argued that questions about the impact, meaning and significance of the illness and/ or presumed diagnosis should be incorporated into routine assessment. The reviewed evidence supports the use of cognitive therapy to target specific appraisals, i.e. appraisals of threat and/ or shame. In terms of therapeutic implications, these findings indicate a need to focus the individual's relationship with the voice, testing and re-evaluating beliefs about the power of the voice and paying attention to possible shame-based origins of feeling subordinate to others. It also suggests that targeting appraisals about perceived threat from the persecutor as well as a focus on resolving appraisals of entrapment in psychosis may be beneficial in reducing depression in people experiencing psychotic illness. Promoting a sense of control through, for example, relapse prevention strategies may aid this process. Unemployment also appears to be a predictor for depression and should be a legitimate focus for mental health services.

1.5.4. Future research

In order to more fully understand *how* appraisals about psychosis relate to the emergence and course of depression, it is necessary to measure these across time. As most of the reviewed studies are cross sectional, this negates any inferences about causality or stability over time. Longitudinal research is required to investigate this. Sample sizes in this area of research are small and replication is required with larger samples to add weight to these findings and allow for examination of whether the reported associations between attributions and depression were mediated by other factors.

The reviewed studies support the notion that psychological therapies which target depression by focusing on reappraising negative beliefs about the diagnosis and illness are likely to promote emotional recovery. However, further research is necessary to substantiate this theory.

Despite the fact that 80 per cent of first episodes of psychosis emerge between the ages of 16 and 30 years (Lester *et al.*, 2009), all except one of the studies drew participants solely from adult populations. Future research exploring whether similar findings emerge with individuals who are at a different developmental stage would be of real interest. Lastly, this systematic review identified that there is a distinct absence of qualitative research considering the relationship between psychotic illness and emotional dysfunction. Research using a qualitative methodology would allow for an in-depth examination of individuals' experiences of psychosis and depression which was not limited to rigidly defined variables. Qualitative approaches can be particularly useful in exploring relatively new areas of research and can contribute towards the development of theories which can then be subjected to quantitative inquiry.

1.6. Conclusions

Despite a large body of research highlighting both the prevalence and the impact of depression in people experiencing psychotic illness, empirical work exploring the origins of depression in psychosis is sparse and there is a paucity of research with adolescents. Whilst the current literature pertaining to a psychological mechanism can be divided conceptually into two streams, it is unlikely that these hypothesised pathways are mutually exclusive and even less likely that they account fully for the emergence of depression within this group. Undoubtedly, the relationship between psychosis and depression is a complex one. However, if we are to make an impact on the quality of lives and outcome of individuals with psychosis, further research in this area should be a priority.

1.7. References

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2. Bridging chapter

The aim of this bridging chapter is to briefly outline literature relevant to the development of the study's research questions which was not referred to in the previous systematic review.

2.1. Additional background literature

Psychotic illness affects 3.4 per cent of the population over a lifetime (Perela *et al.*, 2007) and 80 per cent of first episodes of psychosis emerge between the ages of 16 and 30 years (Lester *et al.*, 2009). Reliable population based incidence figures for child and adolescent onset psychosis are distinctly lacking (Hollis, 2003) but it is estimated that approximately 200,000 adolescents in Edinburgh, the Lothians, Lanarkshire and South Glasgow are at risk of developing psychosis (Compton, 2001).

Psychosis can have a devastating and wide-reaching impact on a young person's functioning and carries a high risk of suicide (approximately 7 per cent), with the highest risk found during the first years of treatment (Palmer *et al.*, 2005). Research suggests that the consequences of adolescent onset schizophrenia are more severe than those of adult onset schizophrenia, with poorer social adjustment, severe functional impairment and high socioeconomic dependence (Lay *et al.*, 2000; Malla & Payne, 2005). In addition, individuals who have onset of psychosis in adolescence tend to have significantly longer duration of untreated psychosis (DUP) (Ballageer *et al.*, 2005). This concept has attracted considerable interest and a number of studies suggest a significant relationship between longer DUP and poorer clinical and functional outcome (Malla & Payne, 2005).

Research with adult populations with psychosis finds that these individuals experience a high degree of co-morbidity and report significant emotional distress. As detailed in the previous chapter, depression occurs in 80 per cent of patients at one or more phases of first-episode psychosis and is associated with acts of deliberate self harm and suicidal thinking (Upthegrove *et al.*, 2010). Indeed, the prevalence of suicidal behaviour during the early phase of psychosis has been shown to rise in parallel with the severity of depressive symptomatology (Gonzalez-Pinto *et al.*, 2007). Furthermore, in this population, depression predicts poorer outcome, including more frequent psychotic relapses and hospitalisations and poorer quality of life (Buckley *et al.*, 2008). Upthegrove (2009) reviewed the literature on depression in psychotic illness and concluded that whilst there appear to be different

mechanisms involved at different phases of the illness, currently there are no clear answers about the underlying causes of depression in this group.

Social anxiety is also common following psychosis. In the first year following onset of psychosis, 29 per cent of adults with psychosis report symptoms which meet diagnostic criteria for social anxiety disorder (Birchwood *et al.*, 2006). A further 11.6 per cent report clear difficulties in social interaction and/ or signs of avoidance which are not sufficient to fulfil formal diagnostic criteria (Michail & Birchwood, 2009). This co-morbid diagnosis has also been found in 36 per cent of outpatients and is associated with a higher lifetime rate and greater lethality of suicide attempts and lower quality of life (Pallanti *et al.*, 2004). Research suggests that social anxiety is not just an epiphenomenon of psychotic symptomatology and paranoia and that it may have more than one causal pathway (Michail & Birchwood, 2009), although, as yet, these pathways are far from clear.

Turning to qualitative research, whilst to the author's knowledge there is no published research specifically exploring the experience of depression or social anxiety in people with psychosis, previous research of this type has explored the subjective experience of psychosis more broadly. Phenomenological research carried out by Davidston & Stayner (1997) highlighted that first person accounts of psychosis are pervaded by themes of social isolation, loss of interpersonal relationships and a sense of emotional distance from oneself and others. These accounts mentioned a number of barriers to relating to others, including stigma, rejection, unemployment and poverty in addition to impairments in attention and concentration. Participants in this study also described their experience of increased intensity of affect, meaning that emotions with a negative valence (e.g. hostility, anger, disapproval) were especially difficult for them to tolerate, impacting on their relationships with others. Failed attempts to share the burden of their distressing experiences served to further alienate participants.

In a similar vein, Hirschfeld *et al.*, (2005) conducted a grounded theory analysis of young people talking about their experience of psychosis. Participants were asked to reflect on themselves and their lives before, during and after their first psychotic experience. Four themes emerged during the analysis which were common to all young peoples' accounts. The first was 'experience of psychosis', in which young people spoke about how their psychotic symptoms elicited in them extreme emotional states and altered their typical interactions with the world. Within this category all participants described experiencing feelings of deep

unhappiness, thoughts of dying and in some cases, attempts of suicide. The second theme to emerge from the analysis was ‘immediate expression of psychotic experiences’, whereby participants spoke about their immediate coping responses. These experiences fell within two subcategories: ‘avoidance of experience’ in which participants described attempting to ‘block out’ their psychotic experiences; and ‘expression of experience’, in which participants described speaking internally to themselves and their voices, sharing their psychotic experiences with friends and expressing the psychotic phenomena through painting and drawing. The third theme to emerge from participants’ accounts was ‘personal and interpersonal changes’, whereby all participants expressed deeply felt qualitative changes in their experiences of themselves as people and in their relationships. This included experiences of loss, loneliness and alienation, as well as struggles to overcome fears and anxieties about being around and relating to peers. The last theme to emerge from the analysis was ‘personal explanations’, where participants spoke about further reflection and consideration of the impact of psychosis in relation to their lives before the onset of psychosis. In particular, this included attempts to reconcile their current circumstances with their age-related milestones and aspired goals, such as individuation from the family and developing romantic relationships. Of particular interest to the current study was the fact that in narrating their experiences, the majority of participants described difficulties in relating to others and their experience of becoming depressed at some stage during their psychotic illness. Some even described feeling that their experience of depression was more difficult than their experience of psychosis.

2.2 Rationale for current study

Research indicates that depression and social anxiety are common in people who experience a first episode psychosis and can occur at various stages of the illness (Iqbal *et al.*, 2000). However, research in this area is in its relatively early infancy and thus far has tended to focus on the prevalence and course as opposed to the origins of these co-morbid emotional disorders. As highlighted by the systematic literature review in the previous chapter, the sparse quantitative research which does focus on investigating possible psychological factors contributing to the development of emotional dysfunction in psychosis indicates that psychological appraisals, both about the meaning and impact of psychosis as well as the experience of psychotic symptomatology may play a part here. However, it is highly unlikely that this accounts for the full picture.

Previous qualitative research in this area has explored the subjective experience of psychosis and indicates that social isolation and difficulties in relating to others are common experiences, as is the experience of depression and suicidal ideation. However, a comprehensive review of the literature failed to identify any published qualitative research specifically designed to explore the subjective experience of low mood or social anxiety following psychosis.

In summary, findings from adult populations indicate that in the context of psychosis, depression and social anxiety are likely to have significant implications in terms of a young person's ability to adapt to the experience and to reintegrate socially and vocationally, not to mention the further heightened risk of suicide. In light of these implications and given the lack of research in this area, further knowledge about the experience and origins of depression and social anxiety in psychosis is urgently needed.

2.3 Aims of research

The primary aim of this research was to establish a grounded theory of the experience of mood and anxiety related difficulties in young people who experience a first episode psychosis.

Secondly, the research aimed to establish the underlying psychological factors contributing to the relationship between psychosis and mood and anxiety difficulties.

3. Methodology

This chapter will describe the methodological processes undertaken in carrying out this study. It will be divided into five subheadings: 1) Design; 2) Participants; 3) Ethical considerations; 4) Procedure and; 5) Measures.

3.1. Design

The current study employed a mixed-method design with primacy given to the qualitative component (QUAL+quan).

3.1.1. Rationale for mixed-methodology

Unlike purely quantitative methods, which generate hypotheses prior to data collection, a mixed-methods design with an emphasis on qualitative methodology was selected as it would: a) allow for the generation of theory from the collective experiences of young people experiencing first episode psychosis; b) allow measurement of key variables using measures which are well embedded in the literature and; c) allow integration of both the qualitative and quantitative data, adding strength to the core concepts upon which the resulting hypotheses and theory are built. The author approached this study from a pragmatist perspective, utilising a design and methodology best suited to purpose with a view to advancing our understanding of the phenomena under investigation (Barker *et al.*, 2002).

In mixed-methods research, each method informs and develops the other; so called ‘methodological triangulation’ (Mason, 2006). Whilst purist researchers argue against this form of ‘method slurring’ (Baker *et al.*, 1992), a mixed-methods approach has been recognised for allowing a ‘deeper’ understanding of researched phenomena, which are not constrained by pre-existing hypotheses (Barker *et al.*, 2002).

3.1.2. Social constructivist grounded theory

Relatively little is known about the experience of depression and social anxiety in relation to first episode psychosis. Where few theories exist about a given area, qualitative research is often adopted as it allows the exploration of subjective human experience and the generation of theory to understand this experience.

The primary qualitative methodology used in this study was a social constructivist version of grounded theory (Charmaz, 2006). Whilst other qualitative methodologies were considered (e.g. Interpretive Phenomenological Analysis (IPA)), grounded theory was selected for its ‘open’ approach to research and because it facilitates the process of ‘discovery’ of shared experiences, occurring in common contexts (Willig, 2008). Taking a reflexive stance, the social constructivist version emphasises the role of the researcher as an active agent in the co-construction of the narrative, the meaning making process and the interpretation of these narratives. The emergent theory is therefore a context-dependent interpretation of the data made by the researcher (Charmaz, 2006).

3.1.3. Epistemological considerations

The epistemological and ontological stance adopted by the researcher was that of ‘critical realism’, a philosophical approach most commonly associated with Bhaskar (1989). Critical realism subscribes neither to an objectivist nor to a constructionist ontological stance, but is in line with constructivism. According to Charmaz, (2006, p. 130), a constructivist approach ‘places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants’. According to this perspective then, knowledge is context-dependent and therefore inherently biased by the personal and socio-cultural circumstances of the researcher and the participants. The critical realist therefore, aims to gain a better understanding of what is ‘really’ going on in the world yet recognises that all observation is theory-laden and ultimately fallible and therefore may not provide direct access to this reality.

3.1.4. Researcher’s position

The author is a 29 year old, British trainee clinical psychologist. In keeping with the epistemological stance described above, she acknowledges that her own perspective will influence her interactions with those she interviews and her subsequent data analysis. She does not have personal experience of psychosis but has some experience of working clinically with young people and adults with psychosis, both during her training and prior to this as an assistant psychologist. Her interest in the research area was stimulated by this clinical work, in particular by her experience of co-facilitating psycho-educational and therapeutic groups with people with chronic psychotic illnesses in an inpatient setting. This experience highlighted the prevalence of affective disorders in this group of people and led

her to reflect on the onset and development of these difficulties in these patients during their adolescence and early adulthood. This inspired reading around the area and, in due course, a thesis proposal.

The author has no prior experience of qualitative research and therefore approached this research with a mixture of enthusiasm and a healthy level of apprehension. During training, working with young people with complex needs in a Tier IV service has developed her skills in establishing rapport and creating a safe, empathic and non-judgemental 'space' for individuals who may have difficulties with engagement. The author acknowledges that her training in psychology may lead her to interpret the qualitative data in terms of psychological constructs and this may influence the analysis of data.

3.1.5. Research context

This research was conducted during the author's final year of the Doctorate in Clinical Psychology, during a twelve month specialist placement in Tier IV Child and Adolescent Mental Health Service (CAMHS). All participants were in contact with the Early Psychosis Support Service (EPSS) which sits within Tier IV CAMHS. EPSS accepts referrals for young people experiencing psychosis between the ages of 12-21 (presenting to the service before their 19th birthday). EPSS provides intensive intervention, with a recovery approach, based on the premise that there is a three year 'critical period' following first onset of psychosis (e.g. Birchwood *et al.*, 1998). The service aims to minimise or prevent many of the secondary personal, social and occupational disabilities which typically develop following a psychotic episode.

3.1.6. Ensuring rigour and quality

In order to promote reliability and validity of the data, the researcher adopted the four flexible and open-ended principles proposed by Yardley (2000): 1) sensitivity to context; 2) commitment and rigour; 3) transparency and coherence and; 4) impact and importance. Sensitivity to context can be demonstrated through awareness of existing literature, an awareness of the social-cultural setting and of the language and interactions between researcher and participants and how this may influence data and be reflected in the results. It also relates to an ethical obligation for the researcher to be aware of any power imbalances and how the researcher's own actions and perspective may impact on the data collected. Commitment refers to the need for the researcher to develop competence and skill in the

methods used and to adopt an in-depth engagement with the topic. Rigour refers to the completeness of the data collected and of the analysis, e.g. cross validation of emergent themes in the data. Transparency and coherence require clarity in descriptions of how the research was undertaken and the disclosure of all relevant aspects of methodology and process, including the reflexive stance of the researcher. Coherence also refers to the 'fit' between the research question and the philosophical perspective adopted. Lastly, the impact and utility of this study will ultimately be judged by those for whom the findings are deemed relevant. According to Yardley (2000, p. 223) 'the decisive criterion by which any piece of research must be judged is, arguably, its impact and utility'. This is likely to be assessed in terms of whether the research has contributed to our theoretical understanding of a given area and whether it provides any real benefit to those being studied.

3.2. Participants

3.2.1. Inclusion criteria

Broad inclusion criteria were defined for the current study, in an attempt to capture as many of the young people in contact with the service as possible. The study was open to all young people who attending EPSS for treatment following first episode psychosis. As such, the inclusion criteria specified an age range of 12-20 years, which was reflective of the inclusion criteria of the service (those at the upper age limit would have been first seen at EPSS before their 19th birthday).

In addition, it was specified that potential participants were required to have been in active treatment at EPSS for at least three months. This was stipulated to minimise the chance of inclusion of young people who were acutely unwell and/ or distressed, as well as indicating likelihood of ongoing engagement with the service in order to ensure that participants had appropriate support should their participation in the research cause them any upset.

3.2.2. Exclusion criteria

Individuals with autism and/ or a severe learning disability which would limit communication and/ or prevent their ability to give informed consent were excluded from the research.

3.2.3. Response rates

A total of fifteen young people were initially identified by the EPSS team as meeting inclusion criteria and being well enough in terms of their psychotic symptoms to participate. Each of these young people were approached by their key worker and asked if they would like to take part in the research. Of these young people, five declined, giving a response rate of 66.6% (n=10).

3.2.4. Demographics of sample

The 10 young people who participated in the study were between the ages of 14 and 19 (median age 17 years 3 months), who were attending EPSS following the experience of clinically significant psychotic symptoms. In order to protect anonymity, demographic information is presented in Table 1 for the group as a whole. The sample consisted of five male and five female participants with diagnoses which fell within the spectrum of psychotic disorders, including early onset psychosis, psychotic depression, bi-polar disorder and puerperal psychosis. Seven of the participants lived at home with parents or another relative. One lived with their partner, one lived alone and another lived in a residential unit. Four of the young people had not been admitted to psychiatric hospital at any stage, four had been admitted once, one had been admitted twice and another had been admitted on three occasions. Reasons for admission included acute psychotic symptoms, low mood and risk of suicide. Participants had been involved with EPSS between 3 months and 8 years eight months (mean 1 year 4 months). All were taking neuroleptic medication and receiving psychosocial support.

Table 1: Demographic information for participant sample

Demographic information	Number of participants N=10
Sex	5 male 5 female
Age	14 -19 years (median 17 years 3 months)
Ethnicity	9 White Scottish 1 Chinese
Living situation	8 living with parents 1 living in a residential unit 1 living alone
Age first CAMHS involvement	3 - 17 years (mean 6 years 9 months)
Age first Psychosis Service contact	14- 18 (mean 16 years 6 months)
Admissions	4 no admission, 4 one admission, 1 two admissions, 1 three admissions

3.3. Ethical approval

3.3.1. Approval process

Ethical approval for the study was gained from the South East Scotland Regional Ethics Committee 03 (REC reference 11/AL/0019) using the standard Integrated Research Application System (IRAS). Ethical approval for the research was granted following minor modifications to the Participant Consent Form (see Appendix 3 for approval documentation). The study was subsequently reviewed by Lothian NHS Research & Development Office and given approval to proceed. Within the specific site of the research, management approval was granted by the Head of Psychology for Lothian Child and Adolescent Mental Health Services (CAMHS).

3.3.2. Safeguarding participants

3.3.2.1. Informed consent

A participant information sheet (see Appendix) was developed to provide potential participants with clear, comprehensible information regarding all aspects of the study, including consent to take part and steps taken to protect participant confidentiality. As the

research involved young people, the participant information sheet was designed with the full age range of young people in mind, and avoided the use of any technical terms/ jargon which may have been confusing. In particular, it was made clear to participants that they were free to withdraw from the study at any time, taking into account ongoing consent, i.e. participants reserved the right to withdraw from the study before, during or after participation and this would not affect the treatment they received thereafter.

As is usual, it was assumed that all participants over the age of twelve years had the ability to consent to take part. However, it was acknowledged that the experience of psychosis and related difficulties may impact on a person's ability to consent. Therefore, as an additional safeguard to protect participants, each young person's ability to consent to take part in this research was confirmed by their treating psychiatrist prior to consent being gained from the young person.

3.3.2.2. Confidentiality and anonymity

The current study was predominantly based on interview data. Safeguarding the confidentiality and anonymity of participants was therefore, a main concern. This was ensured by the following aspects of the design:

- a) The database containing personal information about participants was stored on a password protected secure NHS network drive and was not uplifted from there.
- b) The researcher transcribed all interviews and designated each participant with a pseudonym and number referring to their position in the interview sequence. All recorded data, transcripts and measures were labelled using these codes. Any identifying features contained in the interviews were removed during transcription. The code key was stored in a password protected computer document on a secure NHS network drive and was not uplifted from there.
- c) A separate database contained the anonymised, non identifiable interview transcripts and assessment data. This database was stored safely in a locked cabinet on NHS premises and was only accessible by the researcher.

d) Designated pseudonyms were used in any reporting and presentation data and outcomes. When presenting direct quotations from interview transcripts any information which may have been personally identifiable was removed or amended.

3.3.2.3. *Protecting participants*

It was acknowledged that talking about the experience of psychosis and associated emotions may be difficult or upsetting for participants. By virtue of the inclusion criteria (outlined above), all participants were in active treatment with EPSS, supported by one or more members of mental health service staff and under the care of a psychiatrist. Participants were encouraged to discuss any issues raised during the interview with these professional supports. Furthermore, each participant was informed at the start of the interview that in the event that s/he became distressed, permission would be sought to inform their key worker so that additional support could be arranged through the team treating them. This was also true of any disclosures pertaining to risk which were made during an interview. In this instance the researcher agreed to discuss this with her clinical supervisor with the appropriate course of action according to NHS policy/ protocol taken from there. In addition, participants were provided with the contact details for a person independent of the study, who they could contact if they were unhappy with any aspect of the research.

3.3.2.4. *Additional safeguards*

It was acknowledged that it was possible that the researcher may experience some distress as a result of listening to participants' accounts of life experiences or mental illness. It was agreed that in this eventuality, this would be managed via regular supervision with the researcher's supervisor, a clinical psychologist, as is in place for all trainee clinical psychologists working within the NHS. Further support was also available from the primary researcher's academic supervisor if required. Clinical supervision also provided a forum for discussion and planning for management of any additional risks which could arise.

3.3.2.5. *Documentation*

The participant information sheet (Appendix 4) was developed to provide potential participants with details of the study, including what would be involved in taking part and

information about confidentiality and the outcome of the research. In order to obtain explicit written consent from all participants, a consent form was developed (see Appendix 5).

3.4. Procedure

3.4.1. Recruitment

Following ethical and management approval, a presentation was given to the EPSS multi-disciplinary team, outlining the background, aims and methodology of the proposed research. Team members were also provided with a written summary of the research protocol and it was agreed that the researcher would attend the weekly EPSS meeting where this research would become an item on the agenda. During these meetings, potential participants were identified according to the above inclusion and exclusion criteria by key workers in EPSS. Before being approached about the study, the ability of all participants to give informed consent was considered in the weekly multi-disciplinary team and sanctioned by the Consultant Psychiatrist. In this case, the key worker informed the young person of the study, invited them to participate and if they indicated verbal interest in taking part, they were provided with the participant information sheet. Those who are interested in opting in were given the option to contact the researcher directly via contact details on the participant information sheet, or were given the option to arrange this through their key worker. During a pre interview discussion in person or on the telephone, the researcher introduced the study, discussed consent and provided an opportunity to answer any questions. For those who verbally agreed to participate a convenient time was arranged for the interview and completion of the quantitative measures, which were completed during a single meeting. Interviews took place no sooner than 24 hours after the initial discussion in order to give participants sufficient time to reconsider and if necessary withdraw consent.

The researcher informed all participants that they were free to change their minds and withdraw from the study at any stage in the process. Prior to giving written consent, all participants were fully informed of the purpose and format of the study, confidentiality and data protection, management of recording and transcription of data. The consent form emphasised the voluntary nature of their participation and asked for permission to publish anonymised quotes.

3.4.2. Qualitative data collection

3.4.2.1. *Open-ended qualitative interview*

Each participant took part in one interview. Written consent was gained from each young person prior to them taking part in the study. Two young people who regularly attended EPSS were interviewed on site. Five young people were interviewed in a quiet, private room in their homes, either because they preferred this arrangement or lived some distance from EPSS. Two young people requested to meet the researcher in a quiet coffee shop near EPSS. One young person was interviewed at the residential school where he lived. All interviews were conducted by the researcher and were recorded using a digital voice recorder. Interview length ranged from 29 minutes to 1 hour and 25 minutes (median =57 minutes).

Interviews were in-depth, open-ended and had an evolving focus. This style of interview and broad opening question was selected to facilitate building rapport with participants, allowing them to express themselves in their own way. This style also encouraged co-construction of a narrative and allowed the researcher's understanding to evolve rather than starting from an assumptive position. This was in keeping with the position of Birks & Mills (2011, p. 75) who state that: 'The grounded theory interview is dependent upon the ability of the researcher to travel a path through the interview with the participant. The greater the level of structure involved, the less able the interviewer will be to take the optimal route'. As the research progressed, the major themes in the interviews were identified and these served to refine the focus of the following interviews.

All interviews were opened in the same way:

'I'm interested in hearing about your experiences that led you to come into contact with EPSS and how they have affected you as a person'.

Responses were followed up with relevant prompts, according to principles of qualitative interviewing (Charmaz, 2006), e.g. 'What was that like for you?'; 'Can you tell me more about that?'. In order to tap into specific autobiographical memories, the researcher asked questions such as: 'Can you tell me about a particular time that stands out in your memory?'; 'Take me back there, describe what was going on for you'.

3.4.2.2. Sampling for grounded theory interviews

Interviews were initially carried out with two participants. The resulting data was then transcribed and preliminarily coded and analysed. Identified themes then informed the focus of the next two interviews. This sequence was repeated throughout the process in order to refine emerging themes and categories and to allow greater sensitivity of the interview questions to participants' experiences, with the hope of increasing the quality of the data. This iterative sampling process was continued until themes were sufficiently rich and dense to make analytical claims, so called 'theoretical sufficiency' (Dey, 1999). The concept of theoretical sufficiency was adopted over that of 'theoretical saturation' (Strauss & Corbin, 2008), which refers to the point where no new themes emerge from the data. The concept of theoretical saturation has been criticised by some researchers as unattainable, since it is not possible for a researcher to evidence that the properties of a category have been coded exhaustively (Dey, 1999). Furthermore, according to Charmaz (2006) this concept raises concerns about foreclosing analytic possibilities.

3.4.2.3. Piloting interviews

As the researcher was new to qualitative research, prior to instigating the research with young people, pilot open-ended interviews were conducted with two adults whom the researcher knew personally, and who had experienced mental health difficulties during adolescence. Whilst the researcher acknowledged that this was somewhat contrived as she knew these individuals socially, conducting pilot interviews with young people from the clinical sample itself and not using the data in the final analysis was felt to be unethical. Audio recordings of these pilot interviews were reviewed by the author's academic supervisor and feedback regarding interview style was given.

3.4.2.4. Research diary

According to Mays & Pope (1996), in qualitative research the primary investigative tool is the 'person' of the researcher. Constructivism fosters reflexivity about one's own interpretations in addition to those of the participants. In keeping with this, a research diary was written throughout the research process with the aim of aiding the researcher's reflection, making explicit the researcher's subjective reactions and interpretations, illustrating the

development of ‘internal processes’ and increasing transparency in relation to the analysis process. After each interview, the researcher wrote field notes on the content of the interviews, emerging themes, thoughts about process and interaction between the researcher and participant and any noted similarities or differences with previous interviews. Throughout the data analysis, memos were written to integrate new insights. These memos were used to increase the level of abstraction, thereby advancing analysis, and to guide theorising about the data (Charmaz, 2006).

3.4.2.5. Qualitative data management

To increase the reliability of the data, high quality digital audio recordings of interviews were transcribed verbatim by the researcher and analysed using QSR International’s NVivo 9 qualitative data analysis software.

3.5. Application and integration of qualitative and quantitative methods

Whilst primacy in this study was given to the qualitative data, in addition to the grounded theory interviews described above, quantitative data pertaining to mood, social anxiety, reflective function and positive and negative symptoms of psychosis was collected. This quantitative data was integrated with the qualitative results in order to provide an additional framework for re-examining the inferences made in the qualitative analysis, further contextualising these results.

3.6. Quantitative data collection

3.6.1. Measures

Immediately after their interview, participants completed the following measures:

3.6.1.1 The Calgary Depression Scale for Schizophrenia

The Calgary Depression Scale for Schizophrenia (CDSS: Addington et al., 1990) is a nine-item measure of depression in schizophrenia, designed specifically to minimise contamination by negative symptoms and the extra pyramidal side effects of neuroleptic medication. The CDSS has been shown to be strongly correlated ($r = 0.91$) with the Beck Depression Inventory (BDI-II: Beck *et al.*, 1996) and is responsive to change in psychotic

symptomatology (Trower *et al.*, 2004). A score of above 6 has been demonstrated to predict the presence of a major depressive episode with 82% specificity and 85% sensitivity.

The CDSS was used to assess for both current and pre-morbid depressive symptoms (i.e. was also used retrospectively as a measure of depressive symptoms in the two weeks prior to onset of psychosis).

3.6.1.2. The Social Interaction Anxiety Scale

The Social Interaction Anxiety Scale (SIAS: Mattick & Clarke, 1998) is a 20 item scale measuring anxiety concerning interpersonal interactions. Each item is rated on a four point Likert scale. The SIAS has received extensive validation. Using a cut-off score of 36, the SIAS has been shown to discriminate between social anxiety, other anxiety disorders and community samples with a sensitivity of 0.93, specificity of 0.66, positive predictive value (PPV) of 0.84 and negative predictive value (NPV) of 0.72 (Peters, 2000).

3.6.1.3. The Questionnaire about the Process of Recovery

The Questionnaire about the Process of Recovery (QPR: Neil *et al.*, 2009) is a 22 item service user rated assessment of personal recovery. Each item is rated on a five point Likert scale from 0 (disagree strongly) to 4 (agree strongly). Two subscale scores are produced. The intrapersonal subscale is based on 17 items (range 0-4, where a high score indicates good recovery). The interpersonal subscale is based on five items (range 0-4, where a high score indicates good recovery). The QPR was developed in the UK with a population who had experienced psychosis. It has been shown to have good internal consistency ($r = 0.94$ for the intrapersonal subscale; $r = 0.77$ interpersonal subscale) and good test-retest reliability for both subscales (intrapersonal subscale: $r = 0.874$, $p = 0.001$; interpersonal subscale: $r = 0.769$, $p = 0.001$) (Neil *et al.*, 2009).

4. Data analysis

In keeping with the principles of transparency and coherence (Yardley, 2000), the process of data analysis and integration of qualitative and quantitative data is outlined below.

4.1. Transcribing interview data

The first stage in qualitative data analysis is transcription of interviews. According to Reissman (1993), it is preferable that the researcher does this themselves, because delegating interviews for transcription may result in omitted sections that may be significant in analysis. Transcribing the interviews was a highly labour intensive process, but in accordance with Yardley's (2000) principle of commitment and rigour, allowed the researcher to achieve an in-depth engagement with the data as opposed to paying someone else to do this. Interviews were transcribed verbatim, including pauses and utterances. Interview transcripts were imported into NVivo 9 qualitative data analysis software to enable data and analytic codes to be more easily managed.

The process of data collection and analysis was guided by the following principles outlined by Charmaz (1990): 1) coding and categorising the data; 2) raising terms to concepts; 3) memo writing; 4) integrating and writing developing theory.

4.2. Coding and categorising the data

The first two interview transcripts were subjected to line-by-line open coding, which involved identifying significant processes and assigning descriptive codes to the smallest meaningful units of text (Charmaz, 2006). The researcher chose to heed the advice offered by Willig (2008, p.39).

'Line-by-line analysis ensures that our data is truly grounded and that higher level categories, and later on theoretical formulations actually emerge from the data rather than being imposed upon it'.

As an illustration of the initial coding process, an extract of the interview transcript from 'Daniel' 1, together with line-by-line codes is provided below:

	Transcript	Coding
Daniel	Erm, it had been partly because I had always been quite acrimonious about my disability and how it affected me, and how I couldn't do things that other people could do/	Conflict. Inferiority. Anger regarding disability.
Interviewer	I see	
Daniel	/ and erm, I also, I also was, er {... 2 sec} at the beginning of 5 th year the work load just got bigger and bigger and I couldn't keep up and I felt like I was sinking/	School work. Not coping. 'Sinking'. Feeling overwhelmed.
Interviewer	Mm-hm.	
Daniel	/ and because of that, I got into a vicious cycle, what happened was, I went to class, I felt like I needed to work more, so I wasn't getting enough sleep, so I wasn't doing well in class, so I felt like I needed to work more, so I didn't get enough sleep and so I wasn't working in class.	Vicious cycle. School work. Performance vs effort. Personal resources. Ability. Sleep. Self expectation. Personal standards.
Interviewer	Yeah, yeah, so you felt you got into a vicious cycle?	
Daniel	Yeah, and that kept going. And also, from like third year I think I fell unrequitedly in love with this girl who didn't even care about me, so that kind of didn't help.	Continuing pattern. Rejection. Self worth. Falling in love. Unrequited love. Impact. Past vs. present. Improvement. Recovery.
Interviewer	Right. That must have been difficult?	
Daniel	I suppose so, but now it's fine.	
Interviewer	Uh-huh. So you talked about a time where you really see that your mood started to drop a bit?	
Daniel	Yeah.	
Interviewer	Tell me about that, that time. What was happening for you?	
Daniel	It was the October holidays, I think. I just stopped sleeping and stopped really functioning and I think my parents took me to various doctors and psychologists and clinical experts, like sleep clinics etc, etc, then I was taken into hospital/	Clear beginning. Sleep. Functioning. Increasing help seeking. Support. End point YPU.

Line-by-line coding allowed the researcher to begin viewing the data analytically and to begin to render some codes into categories (Charmaz, 1990). The sets of codes resulting from this process were then compared, allowing for identification of common ideas and themes inviting further investigation. These themes refined the focus of the subsequent interviews, in other words, emerging theoretical categories shaped the data collection. To facilitate reflection, field notes were made after each interview, recording observations about process, content and emerging themes.

To increase methodological rigour, the initial coding structure and strategies for coding were reviewed by the researcher's academic supervisor in addition to being checked by an independent rater, experienced in qualitative research methods.

4.3 Raising terms to categories

During the early stage of analysis, the initial codes which appeared more frequently or were more significant were used to summarise the data and condense it into tentative, low-level categories. This allowed the researcher to start to take the data apart and frame analytic questions about it. The process of raising terms to concepts was facilitated by two processes: continued questioning of the data and constant comparison of the data. During the first of these processes, when studying the data, the researcher was mindful to continually ask of the data: “how?”; “why?”; “under which conditions?”; “with which consequences?” (Charmaz, 1990). During the process of constant comparative analysis, similarities and differences between interview data, categories and concepts were examined and re-examined repeatedly (with reference to memos and field notes). Through this continuing process, higher level analytical categories were generated. Having identified a category or link between categories, the researcher actively looked for ‘negative cases’, i.e. instances that did not ‘fit’, with the aim of arriving at an inclusive account of participants’ experiences and adding depth and density to the emerging theory (Willig, 2008).

This process of refining themes and categories was continued until the researcher considered that ‘theoretical sufficiency’ has been achieved. This was in line with the definition outlined by Dey (1999, p. 117): “the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications”.

4.4. Memo writing

According to Charmaz (1990, p. 1169) ‘memo writing gives the researcher a tool for engaging in an extended on-going dialogue with self’. Throughout the process, the researcher utilised memo writing to facilitate integration of new insights and increase the level of abstraction of the data. Memos allowed the data to be viewed from a variety of perspectives. Later memos incorporated existing theory as the grounded theory developed (examples of memos appear at Appendix 6).

The researcher recognised that her preferred mode of learning was visual, therefore, in tandem with memos, relied heavily on the use of diagramming; ‘conceptually mapping analysis throughout the process’ (Birks & Mills, 2011 p. 103). Examples of diagrams appear at Appendix 7. To capitalise on this mode of learning, during the early stages of analysis, the researcher wrote key words, phrases and codes on post-it notes and stuck these on a blank A2 sheet. This allowed for organisation into ‘moveable’ categories, where ‘thought branches’ grew from certain categories. These codes were continuously revised and modified in the light of further interview transcripts. At this point of analysis the codes were entered into NVivo 9 to support the analysis process. It should be noted that although the use of such computer packages allow data to be sorted more quickly than might be achieved by hand, the researcher must still interpret and conceptualise data, examine relationships, document the process and ultimately, develop theory (Bringer *et al.*, 2004).

In moving towards developing theory, the content of the interviews and emergent categories were considered in light of the existing literature related to psychosis and emotional dysfunction. A second literature review was undertaken, to cross-validate themes emerging from the interviews. The final model evolved from continuous interaction with both the data and existing literature.

4.5. Development of themes and categories

After the first two interviews, common ideas were emerging which appeared to merit further investigation in subsequent interviews. Participants’ narratives clustered around themes relating to coping, isolation, relationships, identity, the impact of psychosis and adapting to psychosis. Young people talked about their experiences in terms of a ‘journey’, tending to

describe the onset of their difficulties, their attempts to manage this and how things developed from there. Adaptation to psychosis was described very much in relational terms, as illustrated by the following memos written after coding the first four transcripts and then following coding of all transcripts:

Psychosis as a ‘relational thing’ (written after coding interview four)

I’ve just been back and read/ listened to all four interviews and been struck by how strong the interpersonal theme running throughout them is. Life really is about people, relationships. How we relate to others. How they relate to us. How we see ourselves through the eyes of others. Likewise, these kinds of psychotic/ mood related experiences are described in terms of people and relationships, more than they are about the actual experiences themselves. I am suddenly very aware of what a stark contrast these narratives provide to traditional diagnostic classification of illnesses like schizophrenia. Young people are not focusing on their symptoms per se, but on how these things impact on their relationships, and their identity, both in their eyes and in the eyes of others. Psychosis is experienced as a relational ‘thing’.

Additional note (written after coding interview 10)

The interpersonal ‘stuff’ is absolutely key in all of the participants’ experience, i.e. the experience of psychosis is intrinsically one that is defined in relation to others.

This seems to be the ‘active ingredient’ if you like. In particular, participants talk about:

- *How these experiences set them apart from others.*
- *How these experiences change a) how you relate to yourself; b) how you relate to others, and; c) how others relate to you.*

In addition, when they talk about getting better, a key ingredient is talking about ‘it’ with others, having ‘it’ be accepted and understood by others.

Adapting to diagnosis and life with psychosis was another significant topic that most participants referred to. The memo below illustrates the early development of this idea into what would become a key category ‘*facing diagnosis*’.

Memo: Diagnosis vs identity

There seems to be something really powerful for participants about diagnosis. Some young people have welcomed or just simply accepted a diagnosis and perceive it as helpful in terms of making sense of their behaviour or difficulties, whereas some perceive it as a 'life sentence', and/ or actively 'fight' being labelled, even to the extent of minimising/ denying symptoms to professionals involved in one case.

It's as if 'psychosis' (or whatever the diagnosis) is an additional 'layer' in terms of a person's identity, which the young person then has to carry around with them. The person can 'become' the diagnosis, experience it as something which belongs to them, or completely reject it. For example, compare:

Beth 2: "Well, the friends I've got obviously know about my bipolar"

with...

Barry 7: "Well like when I first meet someone I tell them that I'm bipolar, aye"

with...

Will 6: "I didn't tell them a lot – well I did tell them a lot but like I wasn't telling them stuff I didn't want to tell them. So I couldn't get labelled, and I still do it to this day and like people say you shouldn't do that, and I know I shouldn't do it but I don't want to be labelled like that".

Additional note: doing vs being.

*It seems that when it comes to this, some participants are '**doing**' (living with psychosis), some are '**being**' (being psychotic; being bipolar) and some are '**avoiding**'.*

Participants tended to narrate the 'sequence' of their experiences, i.e. from when they first noticed things were beginning to change, to the current time. As the research progressed, a broad framework began to emerge which encapsulated the experiences that participants had been describing. The overarching theme, consistently evident in participants' narratives was one of '*a developmental trajectory of psychosis*'.

4.6. Integration of qualitative and quantitative data

In developing categories and subcategories, scores from the CDSS, SIAS and QPR were also considered as part of the process of analysis, adding to the level of interpretation. For example, in the category ‘facing diagnosis’, some participants described experiences in relation to welcoming the diagnosis and others described rejecting the diagnosis. Examining differences in scores on the quantitative measures for participants in each of these subcategories added another ‘layer’ of interpretation to the developing theory. Essentially, utilising the quantitative data in this way provided an additional framework for re-examining the inferences made in the qualitative analysis.

4.7. Reflections on the research process

It would be fair to say that this research process has been a steep learning curve. I was glad to have a thesis supervisor who was experienced in qualitative and mixed methods research and contact with other trainees who were also undertaking grounded theory research. Although to begin with, I was somewhat daunted by the thought of conducting in-depth open-ended interviews (in the absence of what I perceived to be the ‘safety’ of a semi-structured interview schedule), I enjoyed the sense of ‘travelling a path through the interview’ with each young person (Birks & Mills, 2011) whilst maintaining an open and curious stance. Freeing myself from assumptions in this way allowed the participants to talk about what was really meaningful and important for them in terms of their experience and recovery. I was taken aback by the fact that even in the face of their on-going difficulties, these young people had given up their time to talk to a total stranger about their personal experiences.

I was struck by the strong interpersonal theme running throughout the interviews, as recorded in the previously documented memo ‘*psychosis as a relational ‘thing’*’. This led me to think about my clinical work, and how, without necessarily realising it, it is all too easy to focus on symptoms, with an implicit assumption that these will be core in terms of a young person’s distress, whereas what seems to be key is relationships and the experience of being understood and accepted by others. I feel better informed for having undertaken this research and hope that my own clinical practice will improve as a result.

Undoubtedly, the emphasis on a qualitative methodology allowed me to gather much richer data than would have been afforded by purely quantitative methods; something which, given the limited research in this area, I feel is key to the advancement of knowledge and theory.

Overall, whilst it was certainly a labour intensive and tiring process, I found my first experience of qualitative research interesting and enjoyable. In particular, I was struck by how ‘all consuming’ the process of qualitative research is, and how apt a term ‘immersion’ in the data is. Indeed, after overcoming my initial hesitance to commit to and record my own ‘sense’ of the data, it was this very process of living and breathing the data that I found so appealing.

5. Results

This chapter presents the development of grounded theory which emerged from analyses of the interview data. Seven key categories emerged, describing what the author observed as being developmental trajectory (stages) of young people experiencing and adapting to psychosis. They are presented in a developmental sequence because this reflects how the narratives unfolded. The subcategories describe the concepts and underlying psychological processes underpinning each of these stages. However, whilst these concepts and processes are *linked* to particular stages, they are not *unique* to those stages. Some of these processes recurred at different phases of this developmental process. Therefore, some will be represented in more than one category.

In the first section of this chapter, the categories and their subcategories will be presented sequentially, with exemplar verbatim extracts from the data. Where relevant, reference will be made to quantitative data in order to add triangulation and provide further context for discussion. The second section will present interpretation and discussion of the key categories, concepts and processes, with integration of existing literature. This will be followed by a summary of the grounded theory.

The key categories and the sub-categories contained within them are depicted in Figure 1 and discussed in detail in the following section.

The overarching theme (core category) was one of *the experience of a developmental trajectory of psychosis*. Within this, participants spoke about their experiences in terms of seven broad categories: *the build up*, *coping*, *breaking point*, *facing diagnosis*, *impact of illness*, *getting stuck* and *moving on*.

All ten participants spoke to some extent about *the build up* to the problems they had experienced. Within this first broad category, participants spoke about *abuse*, *isolation*, *loss* and *changes in mood*.

The second broad category to emerge from participants' descriptions of their experience was *coping*. Within this, participants spoke about *vicious cycles* and *escape*.

The third category related to *reaching breaking point*. In relation to this broad theme, participants spoke about *breaking down*, *self destruction* and *others noticing*.

The fourth category which emerged was *facing diagnosis*. In relation to this participants described *welcomed diagnosis*, *diagnosis as a threat*, *fighting diagnosis* and *defending the diagnosis*.

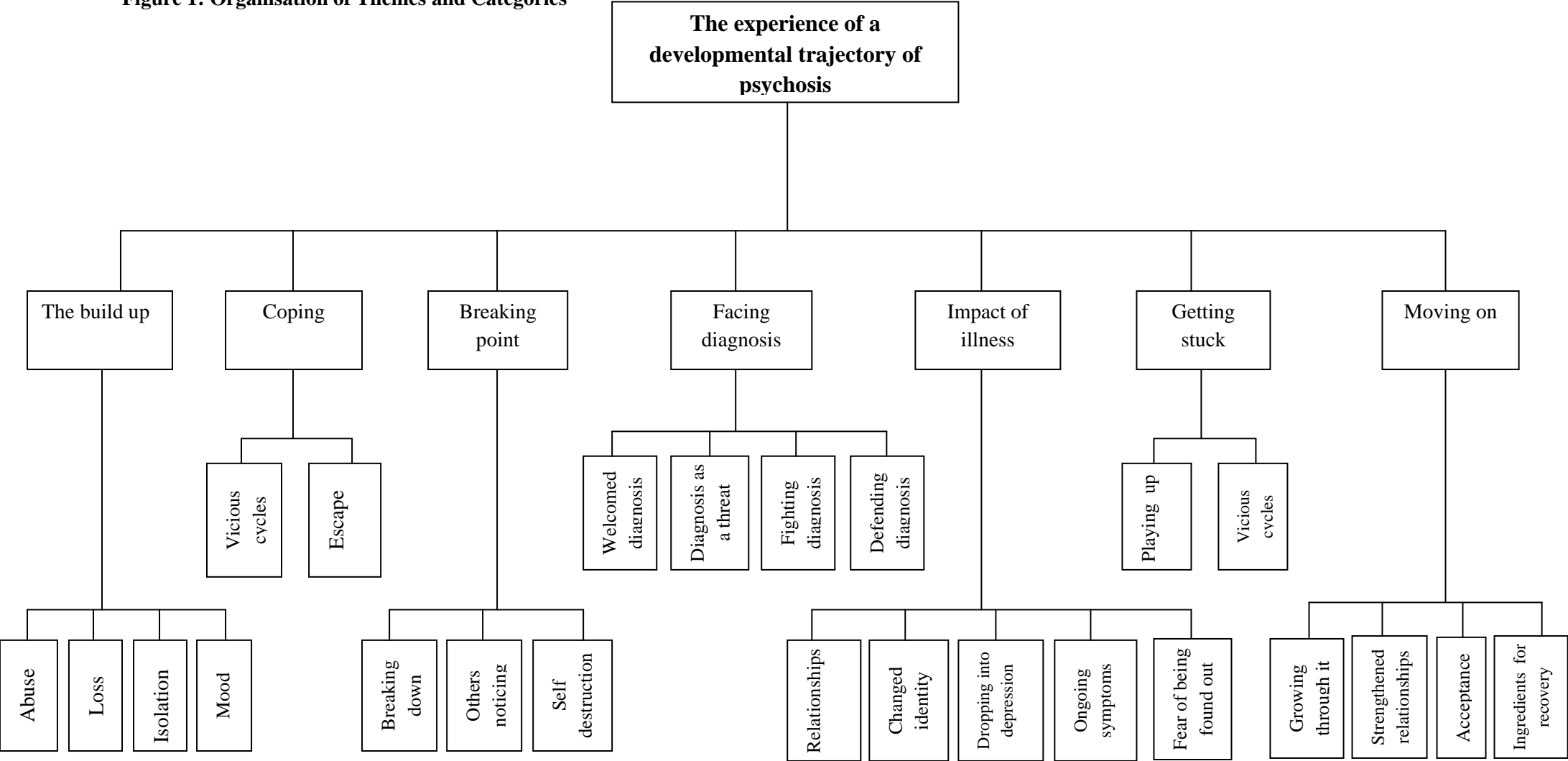
The fifth category related to *impact of illness*. Participants spoke about *relationships*, *changed identity*, *dropping into depression*, *ongoing symptoms* and *fear of being found out*.

The sixth broad category to emerge was *getting stuck*. In relation to this, participants described *playing up* and *vicious cycles*.

The last category to emerge from participants' descriptions of their experience was *moving on*. In relation to this, participants talked about *growing through it*, *strengthened relationships*, *acceptance* and *ingredients for recovery*.

All names identified in the following excerpts are pseudonyms.

Figure 1: Organisation of Themes and Categories



5.1. Interview findings by category

5.1.1. The build up

In providing a context for their current difficulties, all participants described relevant experiences from before the onset of their psychosis and many spoke about what they perceived to be the early origins of their difficulties.

5.1.1.1. Abuse

Four of the participants described experiencing abuse prior to the onset of psychosis. Two participants described physical and emotional abuse from their ex-partners:

Excerpt: Debbie 3

“... and erm, that’s when the abuse really started, like, more mental abuse than anything, but later physical abuse too, and that just tore me to pieces, ‘cause I didn’t realise it was abuse, like, it was my first serious relationship”.

Excerpt: Beth 2

“He strangled me a few times when I was pregnant, it’s left a mark around my neck. He’s pushed me down the stairs too (...) there was a few times I had to get prescribed vallies ‘cause I was that nervous obviously. And like, when I split up from Ethan I was getting panic attacks and stuff and flashbacks and nightmares”.

Two participants described experiencing persistent bullying throughout primary and secondary school:

Excerpt: Daniel 1

“Erm, bullying... well, bullying is another thing that happened. That’s probably a major, major thing that got me down and really kicked my confidence”.

Excerpt: Nick 8

“Er, well it started off, I used to get bullied a lot so this kind of build up of hate and stuff like that has kind of built up over the years since primary to high school”.

5.1.1.2. Loss

Four participants spoke about the death of family members/ friends as significant events in their lives prior to the onset of psychosis:

Excerpt: Barry 7

“Basically I was {... 2 sec}, well I took it really bad, ey. I did nae go to, I could nae go to the funeral because it was that bad, and er it was quite hard because I never went to his funeral and I never went to his grave once since he died, for about two year but when I went I just cried and cried and cried”

Excerpt: Abbie 10

“Well erm, one of my class mates had just died and that’s when it kind of started”.

Excerpt: Will 6

“Well, what is there to say except that I was down in the dumps, I mean I was 12 getting told that one of your friends died (...) I had felt down before that but that was just the final straw”.

Excerpt: Daniel 1

“... but it all pretty much started when my granddad died. I think that’s another aspect. Another layer on the cake of depression (...) I felt like I’d lost my belief then, erm, my faith and my belief in things working out in the end and stuff”.

5.1.1.3. Isolation

Excerpt: Steven described a prolonged period of isolation prior to his referral to the service.

“I was, 2009 well I was in, I was kept in my room. Well I’d been kept in my house by my mum practically for the whole of my life till about end of 2008 (...)I just got used to staying in and losing contact with everybody”.

Excerpt: Tamsin

“Er, I always had to look after my brother, and that made me quite low in mood because I couldn’t like go out with my friends”.

The only negative case in this category was Daisy 5, who did not recall any major life stressors prior to the onset of her psychosis.

5.1.1.4. Changes in mood

Three participants spoke of a noticeable change in their mood in the weeks prior to onset of psychosis:

Excerpt: Debbie 3:

“Erm, at high school it was manic. It was either up, it was either very, very happy or very, very low it wasn’t, it wasn’t a happy medium. And then gradually it just got to a constant low”.

Excerpt: Nick 8:

“Erm I just, for a stage I was in depression, I was just”/

TP: / When are you referring to?

*“It was kind of like, I guess you could call it the ‘run up’ to starting to hear things and see things, it was like, I was just realising that I was really f**ked up from all the stuff I was receiving from other people, all the sh*t that I’ve been given, and I started getting really paranoid about myself and like really thinking about myself in this bad way like just thinking, what am I?, what am I and why am I like this?, and am I a freak,? and you know, having all these questions about myself, so my mood would be depressed”.*

Excerpt: Abbie 10:

“It was like all over the place, like I’d be really happy, then a few hours later I’d be really sad and then I might be really angry and I’d just, it was just like everything was coming out for like maybe a day”.

TP: What was causing it to go up and down and all over the place do you think?

“I don’t know, I just couldn’t control my rhythm and that and everything was all over the place and I was really sad and like alone”.

Negative cases

The only negative case in this category was Daisy 5, who did not recall any major life stressors or a change in mood prior to the onset of her psychosis.

5.1.2 Coping

Participants spoke about noticing deterioration in their mental state, which they were able to recognise in retrospect as the onset of psychosis, and all described the efforts they had made to try and cope with this.

The sense of getting into vicious cycles was captured in the following extract and became a key theme as interviews progressed due to its commonality in participants' experiences:

Excerpt: Daniel 1

"I felt like I was sinking and because of that, I got into a vicious cycle".

5.1.2.1 Vicious cycles

In talking about their efforts to cope with this sense of 'sinking', all participants identified getting into 'vicious cycles'. These can be defined as patterns of behaviour which, although they felt protective initially, had the effect of worsening the young person's situation, by isolating them from others and therefore from potential sources of support.

5.1.2.1.1 Coping alone

Strikingly, for several reasons, all of the participants described coping alone with the onset of psychosis. All of the reasons given for this are outlined below. Most participants described more than one of the following reasons for choosing not to disclose their experiences to another person.

5.1.2.1.2 Fear

For some, the choice not to confide in anyone was by underpinned by fear of consequences, relating to anticipated rejection by family members, fear of hospitalisation and/ or medication or perceived stigma:

Excerpt: Abbie 10:

TP: What did you worry your mum might think, if you told her?

“I thought she might disown me, or not want to have anything to do with me or she might take me to the doctors or something”.

TP: Yeah. What would have been scary about going to the doctors?

“For them to maybe take me in, because I always had dreams that I’d be trapped somewhere, and that I wouldn’t be able to get out”.

TP: Tell me about those dreams.

“I just always had dreams that I was being held down and I wasn’t allowed to go anywhere or anything, and I thought if I go to the doctors, I might be put in hospital or something”.

For Debbie 3 and Will 6, their experiences of their own family’s mental health problems contributed to this fear:

Excerpt: Debbie 3

“Erm, I think I should have got help then. I think if I’d gone to my doctor and went, ‘look, I’m not coping, I want to do this, I’m having suicidal thoughts, I’m hearing things’, erm, ‘what can I do?’, but I was so scared that they’d put me on medication like my mum and I wouldn’t be able to do anything, or they’d take me away, or they’d, I just had this horrendous picture that they would put me in a psychiatric place and leave me there”.

Excerpt: Will 6

*“I didn’t want them to think that I was a crazy f***er because and then I’d get locked up and taken to the Royal Ed because I like I’ve got a little bit of history of mental health in my family, I mean my cousin’s schizophrenic, and my uncle’s schizophrenic and my gran, my mum’s mum, I don’t know if she had any mental health problems but she did have a lot of, like, problems”.*

For Nick 8, in addition to his fear of hospitalisation, the thought of talking to a stranger about his problems further inhibited him from seeking help:

Excerpt: Nick 8:

“That’s the other reason actually yeah, ‘cause erm, you think that you’re going to be put in a mental home, you’re going to be put away and have to have all this help and, I wasn’t confident enough to talk to a person, like somebody I didn’t know, like they had degrees and

stuff, but somebody I didn't know and explain my inner thoughts to them, like my fears and such to them, and I would just freak out thinking right, I'm not going to do that, I'm not going to do that, I'm going to keep doing that for myself, I'm going to keep fighting this because I can".

In the case of Beth 2, she chose not to discuss her developing psychotic experiences due to a fear that her son would be taken away from her by social services:

Excerpt: Beth 2

"... so I thought that they would take the baby off me if they thought I was really ill cause my ex had drilled it into me that it was cause of me and my bipolar that social services were involved, so I was like 'I can't tell them or they'll take Tom off me. Like, so I'll just sort of like, hope it goes away".

Two participants described their experiences of actively conveying the opposite emotion to what they were feeling:

Excerpt: Abbie 10

"Like I would always try to put on a happy face like it didn't bother me (...) I just wanted everyone to think everything was great, but really I felt so sad".

Excerpt: Nick 8:

"Erm, I would still be happy and chirpy around everybody, I would still put on this face, but inside my own self I would be this spiteful, hateful person who was building up, and that's why it built up into this alternate persona".

5.1.2.1.3 Mistrust

For two of the participants, previous experiences of being let down had led them to mistrust others:

Excerpt: Debbie 3

TP: What stopped you from taking to people at that point do you think?

"I couldn't trust them. Like, the people I had trusted had let me down".

Excerpt: Abbie 10

“I just kept it to myself, I didn’t feel like I could trust anyone, I didn’t have like, close friends at the time to talk to them”.

This sense of mistrust was further reinforced by Abbie’s experience of auditory hallucinations:

Excerpt: Abbie 10:

TP: And what stopped you from talking to people about that Abbie? What made you think ‘I have to keep this to myself?’.

“Just because I felt I couldn’t trust them, to tell them, and the voices kept telling me that they were working against me and everything, which made me more scared of telling them, in case it was true (...) It was just very confusing, like I didn’t know who to believe”.

5.1.2.1.4 Personal values

For Nick 8, his personal values contributed to his reticence to share his developing problems with others:

Excerpt: Nick 8:

“Yeah I didn’t want to freak out my parents or I didn’t want to hurt anybody else, I just kind of let myself be like that, I just let myself kind of, its ‘cause, I don’t know, the person I am, I can’t do that to other people, to worry them, I don’t like worrying other people because I want people to think I’m ok, there’s nothing to worry about, because for so long it was just, me at the bottom, everybody else at the top. I don’t care about myself, I’m at the bottom of the pile, as long as everybody is happy. For a long time, for a long time I made other people happy and not myself”.

5.1.2.2 Escape

Several of the vicious cycles described by participants were initiated by a strong urge to escape from their difficulties. These vicious cycles related to drug use, self isolation, truanting, self harm and suicide attempts.

The key theme which emerged from participants’ accounts of attempts to escape was **isolation**.

5.1.2.2.1 Drug use

Four of the participants (Nick 8, Will 6, Barry 7 and Steven 4) described using drugs as a way of escaping from increasingly unmanageable feelings and/ or experiences. All of them recognised negative consequences resulting from this way of coping:

Excerpt: Nick 8

“I got addicted more to the pot because of the bong, because I wanted to have, I mean because I wanted to have bong after bong after bong and just melt my worries away into my mind, and just sit there in a complete daze of your own thoughts. It was the way of escaping for a while, well for a long time”.

TP: Mmm. So you feel it helped you escape? Did it have any other impact on you?

“Erm, well I felt incredible obviously but, well to my mental health, I guess those experiences [psychotic symptoms] just started happening more”.

Will 6 described increasing drug use following the death of a school friend and linked this with increasing paranoia and social withdrawal:

Excerpt: Will 6

“Well it was fine at first but then I started getting involved with, like, the wrong crowd I guess. I was like doing a lot of weed and hash and after about a year I started feeling a lot more paranoid than usual and then my friend died so I went on a bender with the drugs. I went pretty heavy on a lot of stuff. (...) I kind of started to, that’s when my mum will say I started withdrawing back from reality and just started staying in a lot more and then the only time I was going out it was to get drunk and I was like really, really like smoking a lot for about 3 months, 4 months or whatever, how long I was doing it. Then after that I started staying in a lot more {... 2 sec} because I was more paranoid then and, but the reason, when I was staying in a lot more I started getting more paranoid. Even though I wasn’t smoking after that, it was the fact that I was staying in that was getting me even more paranoid”.

Similarly, Barry 7 described using alcohol and drugs as a way of coping with difficult emotions and the impact that has on his mental health:

Excerpt: Barry 7

“... it’s been really hard since he died, eh”.

TP: Yeah. How’s that affected you?

“Well when I found out that he’d died I just went off on one, I just ended up drinking for about three weeks straight I ended up getting addicted to speed initially, and cocaine, the lot”.

TP: So does that have any effect on your mental health Barry, like, when you’ve gone on proper bender?

“Aye, it’s like a spiral, then I end up in hospital or I’ll end up in the cells and in court the next day”.

Steven 4 spoke about starting to use drugs as a means of overcoming social anxiety but developing a reliance on it which had the opposite effect of isolating him from his friends:

Excerpt: Steven 4

“Aye, aye, see that’s really the reason I smoked it, erm in the first place because it gave me that much more confidence, like”.

TP: Did it have any other impact on your life, generally?

“It just made me, well with weed, when you start smoking it, and stop smoking it you like become all like, I dunnee ken, you become all like a weirdo, you just become all like isolated to yourself, you feel horrible, you just feel like you want to { ... 2 sec } like when you can’t get any at the end of it, you just, I’d be with a couple of pals smoking it, but when it runs out they’re all fine with it but when I stopped smoking and there’s none left, see like you’d feel, like you don’t want to talk, see like it’s a feeling like you literally want to box yourself in”.

5.1.2.2.2 Self isolation

Debbie 3, Will and Abbie 10, described self isolation as their way of attempting to escape from difficult emotions.

Excerpt: Debbie:

“Cause I used to have, my, my coping mechanism was, there used to be a lake near mine, and any time I couldn’t cope with people or like, kind of relating to people or even just contact

with people and sometimes even with my own boyfriend at the time I'd just go to the lake and spend like, hours there, miss classes, miss school spending hours calming down, just kind of looking at the water, just isolating myself from everybody and that would calm me down".

Excerpt: Will 6

*"Well, my mum will notice a low day for me, 'cos I tell her, 'look, I don't want anything to p*ss me off today', or I'll end up going crazy, just explode and I tell them to leave me alone and they'll leave me alone in my room, 'cos that's the way I deal with my stuff, I like to be left alone in my room. If anyone like comes near me when I'm angry or like low, it's not helping me, I wanna be alone".*

5.1.2.2.3 Truantiing

Nick 8 described truantiing in order to avoid the bullying he was experiencing at school and the conflict that this then created at home:

"I was just very confused at what to do, I had no idea, because I didn't want to go to school because I knew that he was going to be there and I was going to go through even more hell, and that's why I, that's why I stopped going to school. And my Dad tried to get me up in the morning and I would not want to go and I would be just like, no I'm not going and then we would have, me and my Dad would have humungous arguments about the fact that Id not been going to school".

5.1.2.2.4 Self harm

Four of the participants (Beth 2, Barry 7, Nick 8 and Abbie 10) described using self harm as a way of escaping their problems. This experience was best captured in the following exemplar:

Excerpt: Nick 8

"Obviously it's too, it's just such a stress relief. You get this adrenalin pumping through you, it's like horrible thoughts, horrible thoughts about yourself and tons of crap and then all of a sudden you do that and it's gone, it is literally gone from your mind for a day and then you would just kind of have some cuts on your arms and then the next day I would do it again, just for months and months on end I'd just keep doing it".

5.1.2.2.5. Suicide attempt(s)

Six participants spoke of making one or more attempts to end their life in an effort to escape their problems (Debbie 3, Steven 4, Will 6, Barry 7, Nick 8 and Abbie 10). This experience was best captured in the following exemplar:

Excerpt: Debbie 3:

“I took like maybe half a bottle of them and then I went into a toxic state, acute confusion and based on it I was put in hospital, kind of woke up in hospital and was kind of like ‘what?’ I was like, ‘oh no, I’m locked in’, then spent like a week there and calmed down and realised what had happened”.

TP: What had led you to do that? Take me back to that time, what was the thing that made you think ‘right, I’m going to do that?’.

“Escape. Like, it was the equivalent to my long walks, it was the next level to my walks. It was kind of, I can’t, I don’t see myself getting better, I have no friends now (...) they don’t want to know”.

The vast majority of participants spoke of how the attempts to cope captured in the subcategories *vicious cycles* and *escape* had led to them feeling increasingly isolated, depressed and anxious, illustrated by the following exemplar:

Excerpt: Abbie 10

“... the more I didn’t text my friends or phone them the harder it got and, the more I felt low and the more I felt like I had no friends and stuff”.

Table 2 presents individual participant scores on the quantitative measures. The vast majority (nine participants) were significantly depressed (scores of 7 and above) according to the CDSS in the pre-psychotic (prodromal) stage that this category pertains to (range 9-24, mean=16.3). This suggests that the processes indicated here which lead to a sense of isolation early on, are clearly linked to low mood.

Table 2: Summary of participant scores on quantitative measures

	CDSS Pre-psychotic (retrospective) (cut-off 6)	CDSS Current (cut-off 6)	SIAS (cut-off 36)	QPR Interpersonal Recovery (max score 20)	QPR Intrapersonal Recovery (max score 68)
Daniel 1	21	4	15	<i>19</i>	<i>68</i>
Beth 2	12	6	22	<i>11</i>	<i>51</i>
Debbie 3	23	3	18	<i>15</i>	<i>52</i>
Steven 4	12	2	17	<i>10</i>	<i>50</i>
Daisy 5	1	1	19	9	<i>44</i>
Will 6	12	6	31	8	27
Barry 7	24	6	42	<i>12</i>	<i>43</i>
Nick 8	22	12	21	<i>17</i>	<i>66</i>
Tamsin 9	9	1	24	<i>16</i>	<i>53</i>
Abbie 10	12	10	42	<i>11</i>	23

(n.b. **bold** scores denote clinically significant scores; ***bold italic*** scores denote over 50% subjective recovery)

5.1.3 Reaching breaking point

The third category of participant experiences related to *reaching breaking point*. As illustrated in the previous category, all participants (for various reasons) chose not to confide in anyone else as their psychosis was developing. Breaking point can be defined as the point at which the young person no longer contains these difficulties alone and help is mobilised. All participants' experiences fell within one of the following three subcategories: *breaking down*, *other's noticing* or *self destruction*. A brief description of each subcategory will be followed by an exemplar extract.

5.1.3.1 Breaking down

Breaking down refers to the moment where participants described no longer being able to contain their emotions and experiences, with these 'spilling out' (being disclosed) to someone else. This experience was reported by Nick 8:

Excerpt: Nick 8

*"... then one day I broke down and I could not take it and kept on screaming those things like f*ck off, leave me alone, and my friend at first thought it was him, and I had to explain to him that it's not you, it's this voice, and that made me feel so good".*

Of additional note in relation to quantitative data, of all participants, Nick 8 described coping alone with his developing psychosis for the longest period of time. He described repeating these patterns of maladaptive coping for around three years prior to reaching 'breaking point' (described below) whereupon services were accessed. In keeping with this, according to his clinical notes, his duration of untreated psychosis was by far the longest of all the participants (184 days). Nick's score for depression in the pre-psychotic stage was very high (22, cut-off of 6) and his score for current depression (12) was the highest of all participants, indicating significant emotional dysfunction associated with his coping strategy and the resultant long-term isolation.

5.1.3.2. Others noticing

Five of the participants (Daniel 1, Beth 2, Daisy 5, Tamsin 9 and Abbie 10) described reaching a point where changes in their behaviour and/ or functioning were noted by others around them and help was mobilised from that point:

Excerpt: Beth 2

"... and eventually that came to a head, cause I can't remember, I think I was just sleep deprived and like, my ex Ethan was like, shouting at me about something and I just snapped and I was like 'You! It's you the Devil's using' and he was like 'what are you talking about?' and then, cause that didn't make sense he went and he got my neighbour Tracy through and then she figured out, she was like 'you need to get her up to the hospital, she's really not well'".

5.1.3.3. Self destruction

Four of the participants (Debbie 3, Steven 4, Will 6 and Barry 7) described their experience of reaching a point where they no longer felt able to cope with their feelings and experiences and made an attempt to end their life, which signalled to others that they were in need of help.

Excerpt: Debbie 3

"Erm, I think the fact that I didn't speak to anyone about any of those issues {... 1 sec} erm, properly kind of led to almost like a self destructive part in, isolation, kinda, bottling it up, then getting to the point I couldn't cope and then harm breaking out afterwards (...) it got to the stage, I described it to my key worker, it got to the stage where you would look round the room and you would maybe see the most brutal way of killing yourself, like whacking your

head off the corner of a table until you die erm, but really fundamental basics of how to really harm yourself or disembody yourself. (...) and then that kind of eventually led to the overdose cause it was like, I've just had enough of feeling like this, I'm going to, I'm going to do this {... 1 sec} and then I took maybe like half a bottle of tablets”.

5.1.4. Facing diagnosis

Seven participants spoke of facing diagnosis. Their experiences fell within three subcategories. For four participants, diagnosis was helpful and welcomed. Two participants experienced it as threatening. Two participants described actively avoiding a diagnosis and two spoke of it in terms of a part of their identity that they would defend.

5.1.4.1. Welcomed diagnosis

For Daniel 1, Beth 2, Tamsin 9 and Abbie 10, being given a diagnosis was, overall, experienced as helpful. For Abbie 10, diagnosis provided an explanation for what she had been experiencing thus instilling a new sense of hope for the future:

Excerpt: Abbie 10

“It actually makes me feel like a bit more positive, like I’m not a freak. And there are other people out there who have had the same experience and stuff, so it does make feel a bit more positive for the future”.

For Tamsin 9, diagnosis carried with it some reassurance that other people understood what was happening:

Excerpt: Tamsin 9

TP: Yeah, so you just had to accept it. So was the diagnosis Tamsin, of psychosis, was that helpful, or unhelpful or just neutral?

“It was helpful”

TP: Ok. What was helpful about it?

“Mmm, like they knew what my illness was, so it was good that people knew”.

Beth’s experience of diagnosis was mixed. Initially, she experienced it as unhelpful and stigmatising:

Excerpt: Beth 2:

... *“but then when I did get diagnosed bipolar ken, it was still like, well, him and my step mum started making their own diagnoses, ‘aye, you have depression and bipolar’, I was like, ‘no, I just have bipolar’. Neither of them really understands it. They think they do and then like they were shouting at me about it which doesn’t help”.*

TP: Yeah. what, what... {1 sec} that time you’re thinking about where they were shouting at you and that, what do you remember?

“I can’t even really remember what it was he was shouting about it. Just screaming about in the middle of my gran and grand dad’s street, like ‘cheers for telling the whole of Edinburgh I’ve got bipolar, thank you’.

TP: Right. Was that quite soon after your diagnosis?

“Erm maybe about a year or two after. He was basically, from what I remember, he was basically saying I was a loon. I was like ‘cheers’”.

However, more recently her diagnosis has become helpful in terms of allowing others to understand and accept the changes in her mood and behaviour:

Excerpt: Beth 2:

“Well, erm, now my pals know that I’ve got bipolar and it doesn’t bother them. So, it doesn’t really affect them that way, like, obviously, they understand, I’ve explained the basics of it, so that they know if I’m up or down basically, so they know not to take it personally if I’m up and I say something silly or anything”.

Daniel 1 described how his diagnosis gives him licence to get away with saying things that might upset others:

Excerpt: Daniel 1:

“... sometimes I say the wrong thing and sometimes he says the wrong thing and then regrets it later. And so do I. I still do but it’s not as big a deal anymore, I just put it down to the illness [laughs]. It’s quite an excuse now “.

5.1.4.2. Diagnosis as a threat.

Debbie 3 spoke about her experience of diagnosis as something terminal, which instilled a sense of hopelessness, thereby affecting her motivation to engage with treatment strategies:

Excerpt: Debbie 3

“It was like a death sentence. I just couldn’t see it going any quicker or getting any better. Cause I’d hear about people who had been depressed for like five years, like all their teenage years and I was like ‘I do not want to spend all my teenage years being depressed’, um, it was really difficult, you just, you just couldn’t see the point in doing exercises, you couldn’t see the point in taking your pills”.

Daisy 5 described her worry relating to the potential impact that sharing her diagnosis would have on her future prospects:

Excerpt: Daisy 5

“It’s like a work support scheme from the Job Centre. I had this interview and I got upset because the question came to me, erm I can’t remember now. I think it was erm, have you ever been unwell or something”.

TP: Right. How did it make you feel when they asked you that question? Can you remember how you felt?

“Upset, I think. I was crying. ‘Cause I didn’t want them to know”.

5.1.4.3. Fighting diagnosis

Nick 8 described his on-going ‘fight’ against diagnosis, despite acknowledging symptoms for several years:

Excerpt: Nick 8

“I started, I mean I had three years to work it out, I worked out that I had symptoms of schizophrenia, of multiple personality and all that kind of stuff, but I kind of fought it so much, that’s why I feel as though I don’t actually have it, like I do have symptoms of it, but I don’t actually have it, like I do have symptoms of it, but I don’t actually have it if you know what I mean, but like they didn’t want to diagnose me at CAMHS either”.

Will 6 described the prospect of diagnosis as something so threatening that he had spent several years concealing and minimising his psychotic symptoms, not only from friends and family but also from the EPSS, with clear implications for his treatment and recovery:

Excerpt: Will 6

“I didn’t tell them a lot – well I did tell them a lot but like I wasn’t telling them stuff I didn’t want to tell them. So I couldn’t get labelled, and I still do it to this day and like people say you shouldn’t do that, and I know I shouldn’t do it but I don’t want to be labelled like that, I don’t want to tell them the stuff that potentially would put me like that. That’s why I told the YPU that I only want them to help me with my anxiety and stuff like that. That’s why like I hardly get questioned about my hallucinations and stuff like that ‘cos I do deal with it, I know I do deal with it but there’s times where I don’t deal with it as well as I potentially could, but I don’t tell them that”.

5.1.4.4. Defending the diagnosis

Two of the participants spoke about their diagnosis in terms of a part of themselves which they were compelled to defend:

Excerpt: Beth 2

*“... thinking about it I ken myself it’s not that bad, it’s not that annoying, I do have friends who don’t care and it doesn’t annoy them so it’s like if you have a problem like that it’s like f*ck you, I’ve just got to that stage, if you’ve got a problem with my bi-polar I don’t even want to speak to you, go away”.*

For Barry 7, when meeting someone for the first time, the immediate disclosure of his diagnosis appears to serve a protective function, in terms of a ‘pre-emptive strike’, allowing him to quickly reject those who are likely to stigmatise him.

Excerpt: Barry 7

*“Well like when I first meet someone I tell them that I’m bipolar, aye, then if they can’t accept it they can f*ck off”.*

To reference negative cases, Steven 4 was the only participant who did not make reference to diagnosis at any point during his interview.

5.1.5. Impact of illness

5.1.5.1. Relationships

Nine of the participants spoke of the perceived impact that their illness had had on their relationships with others. Themes related to changes in their relationships (in some cases related to a sense that their identity was now different in the eyes of others), relationship breakdown and loss of friendships as a result of the illness. These experiences are best illustrated by the following exemplars:

Excerpt: Beth 2

“Well I don’t really, I don’t speak to my dad anymore. He kicked me out but, I don’t know. He just wasn’t very understanding about the whole bipolar thing (...) even once I got diagnosed, sort of, my dad didn’t understand that sometimes the stuff I do when I’m manic isn’t stuff I would normally, normally do”.

Excerpt: Will 6:

*“Well you know who your true friends are when you come in a predicament like mine and there was only a few that still kept in contact with me and erm like they got a little bit annoyed because I’d have to take a month like trying to get me out, they just got p*ssed off I guess and they stopped trying (...) No, I’ve got like no friends now. It doesn’t even bother me saying it. It used to bother me saying it but yeah, I know for a fact that I don’t now”.*

5.1.5.2. Changed identity

Two participants spoke about their sense that their identity had changed since becoming ill and the knock-on effect they felt this had in terms of their relationships:

Excerpt: Debbie 3:

“Yeah, your self-perception or your relationships completely change, the way they see you and the way you see yourself completely changes and you kind of turn into this victim, they kind of pity you more than anything, it doesn’t turn into a loving relationship, people just pity you and eventually it just turns into loathing ‘oh I don’t want to be near you’, almost like mental illness is contagious”.

Excerpt: Daniel 1

“I remember sitting there and he was trying to talk and trying to encourage me to talk and I just couldn’t talk, I just couldn’t think of anything meaningful to say”.

TP: Right {... 2sec} so were you just kind of sat in silence or, just?/

/” Yeah, sat in silence just playing with the keyboard, and erm, just basically sat in silence”.

TP: Mm-hm. What was that like?

“Harrowing (...) Because he was there and he wasn’t really. It didn’t feel as though he was there in my company, he was just there in the company of a guy who’s depressed”.

5.1.5.2.1 Feeling different to others

Two of the participants described how their experiences had led to them feeling different to others and how this set them apart from people:

Excerpt: Abbie 10

“Yeah I feel like I’m the only one who’s experienced the thoughts I have, and that I’m the only one out there who has like anger for no reason and stuff. It’s quite horrible”.

TP: Yeah. What effect does that have on you?

“It makes me feel more isolated from people, and it makes me feel I should just, like I just feel left alone”.

Excerpt: Tamsin 9

“It was kind of a difficult thing to come to terms with, because it was an illness, and normal people don’t have illnesses”.

TP: Tell me about that Tamsin.

“Er, it just made me feel that I might not get on anymore with other people”.

5.1.5.3. Dropping into depression

A common experience after diagnosis was depression. Six participants clearly described reasons for this drop in mood. Themes related to *loss of hope, loss of control, missing out, stigma* and *on-going psychotic symptoms*.

5.1.5.3.1 Loss of hope

Excerpt: Debbie 3:

TP: Yeah. When you look back at that time now, what was going on in your mind to lead to those times when your mood dipped?

“Erm, just not seeing light at the end of the tunnel was the biggest one (...) It was like a death sentence. I just couldn’t see it going any quicker or getting any better”.

5.1.5.3.2 Loss of control:

For Daisy 5, the experience of relapse after a period of recovery led her to feel hopeless for the future and suicidal:

Excerpt: Daisy 5:

“There were a few really tough days in that time where I really felt a bit hopeless (...) I was seeing things in my drink again, beasties in my drink and things like that. I wanted to kill myself”.

TP: What was making you feel most depressed about that?

“Because, I’m here again. Being back there” (...) I’d been thinking I was well again, so to have it back again was really hard”.

5.1.5.3.3 Missing out:

Excerpt: Daniel 1:

“That was probably what started the drop [in mood] actually, was, I saw my friends and figured ‘oh my god, look how much I’ve missed, look at the relationships they’ve had, all the experiences they’ve had, all the parties they’ve been to’ and stuff like that (...) It’s realisation, I think that’s the trigger, because I realised I’d missed an awful lot”.

Excerpt: Will 6:

“Yeah, yeah, definitely. I’m not going to lie. I’m not necessarily like comparing myself to friends, but comparing myself to people, what people my age should be doing, it’s like I should be there”.

TP: What impact does that have?

*“Nothing. I just get depressed, I get depressed (...) ‘Cos there’s nothing else going on in my life. I mean like, it’s just another day, same sh*t, different day. I just think ‘what the f*ck am I doing?’ Erm, yeah, it’s like ‘what the f*ck am I doing with my life, there’s nothing else going on’, just depressive thoughts, which make me more low.*

5.1.5.3.4 Stigma

For Beth 2 and Debbie 3, the experience of stigma led to deterioration in mood. Beth 2 described a clear change in her functioning as a result of this:

Excerpt: Beth 2

*“...he’s been posting sh*t about me all over facebook, saying like ‘oh I’m concerned about my son because my ex has bipolar’, like making me out to be a right loony and that (...) and then a few days later I’d started to feel a bit sh*t and then, aye, last week I started feeling really sh*t”.*

TP: So, when things are like that, how does that affect other areas of your life?

“I don’t really eat cause everything tastes bland and boring when I’m down, it’s weird. I just, I just want to sleep and not get out of bed. When I’m down like, everything bores me, like nothing on the telly is interesting, going out sounds crap, staying in sounds crap, It’s weird. I can’t... {1 sec} Like, if it’s really bad I’ll feel like I want to kill myself by the end of it, like, I can’t see the point of living and feel like I’d be doing people a favour or something”.

5.1.5.4 On-going symptoms

Three participants (Will 6, Abbie 10 and Barry 7) described how on-going psychotic experiences were contributing towards them feeling depressed and anxious, illustrated in the following exemplar:

Excerpt: Abbie 10

“Like when I’m by myself I feel like there’s cameras’ watching me. Or like the satellites are going through the roof and they can see me, and like everybody can see me no matter who you are”.

TP: Mm, yeah. So you feel like you’re constantly being watched all the time. Does that have an effect on how you feel in terms of your mood or your worry?

“It makes me feel sad that like, that I’m alone and there’s nobody around, and that I just feel really down and low”.

These experiences are reflected by scores on the quantitative measures. In contrast to all other participants, none of whom scored in the clinical thresholds for either the depression or anxiety measure, all three participants in this category showed significant levels of affective dysfunction. According to the CDSS, Abbie 10 was currently experiencing a major depressive episode (score of 12, cut-off of 6) in addition to clinically significant social anxiety according to the SIAS (score of 42, cut-off of 36). Similarly, Barry 7 was experiencing clinically significant levels of social anxiety (score of 42) and sub-clinical levels of depression (CDSS score of 6). Will 6 was experiencing subclinical levels of both social anxiety and depression (SIAS score of 31 and CDSS score of 6).

5.1.5.5 Fear of being found out

Four participants described strong feelings of anxiety related to a fear of their illness being ‘found out’ by others. In all four experiences, this led to anxiety about spending time with other people and therefore a tendency to self isolate:

Excerpt: Beth 2:

“I was always paranoid, like ‘people well know’ (...) After I’ve been manic I always think afterwards ‘oh my God, people are going to know something’s up, I wasn’t acting normal, I was acting so strange, somebody’s going to know something’ and that made me feel worried about seeing people”.

Excerpt: Debbie 3:

TP: And when did you first really get those feelings, intense anxiety about being around other people, interacting with other people?

*“Erm, mainly college. Cause like ‘sh*t, will they realise, will they know something’s wrong with me, can I handle the criticism this week? Am I going to break down in class? Stuff like that”.*

Excerpt: Nick 8:

“I would just sit there in complete silence and sometimes I would go crazy with my own thoughts, but it’s better than being around other people because, they freaked me out, like

being around other people because I'd be thinking that they were saying things about me or thinking things about me, and at one stage I actually thought I could hear other people's thoughts as well, so it was really, really freaking me out so, and the way that some people looked at me, I thought they were judging me in some way".

Excerpt: Barry 7

*"Well, I end up agitated in hospital, that's the only time I end up getting agitated, apart from when I'm walking past big like, like big, like loads of people, like c*nts like a big group of teenagers, I cannee walk past them cos of my bi polar, it's like they're watching, looking at me (...) It's just like, I get paranoid"*

TP: What do you worry about, like what's the worse bit?

"Like they're all staring at me, like they know something's up. When I'm walking past people, my legs start shaking".

5.1.6 Getting stuck (more vicious cycles)

Excerpt: Debbie 3:

"It's just so hard not to get stuck in it".

Many of the factors described above contributed to a sense of getting 'stuck' in their illness. Debbie 3 described 'playing up' to the more fragile identity perceived by other people in her life, which in itself led to a vicious cycle:

5.1.6.1 Playing up

Excerpt: Debbie 3

"... and I was like 'I won't be like that, I promise, I'm well now, I'm well now' and she was like 'no, you're fragile, you're weak'. That's what people's perceptions are of you and you kind of live up to that almost, like 'I can't do this' or 'I'm depressed' and then as you get better you realise that you're not but then that causes more conflict because they're like 'well you are, you've just been in hospital, how can you say that you're coping when that happened? (...) it just makes me feel worse about myself, that's even worse, the vicious cycle is that the more they leave, the more they kind of see that, the more I'm going to play up and go 'oh, I can't do this, I can't do this', cause I feel less than human, really".

5.1.6.2 Vicious cycles and escape

In an attempt to cope with and adapt to ‘life with psychosis’, the vast majority of participants described experiences of falling back into vicious cycles or making attempts to escape from their experiences (described in detail previously in the second category ‘*coping*’). The processes at hand here were the same as those described earlier and therefore, for the sake of brevity, the full details will not be repeated again here, other than to summarise which participants described getting into which particular patterns of behaviour, followed by an exemplar extract.

Abbie 10 and Will 6 described on-going *self isolation* as an attempt to cope with their psychotic symptoms:

Excerpt: Will 6

“Shutting myself off from the world ‘cause I feel paranoid, like about what’s going to happen if I go out, secluding yourself in your happy spot, this is my safe spot, if you take me out of the safe spot, then I get anxious, if you know what I mean”.

Interestingly, both participants who described on-going self isolation as a means of coping had the lowest scores of all the participants on the QPR. Will 6 scored 8/20 for interpersonal recovery and 27/68 for intrapersonal recovery. Abbie 10 scored 11/20 for interpersonal recovery and 23/68 for intrapersonal recovery. These scores indicate that they perceived themselves to be at less advanced stage of recovery in comparison with the other young people. This suggests that self isolation has a detrimental effect on an individual’s ability to recover.

Nick 8, Barry 7 and Steven 4 described ongoing attempts to *escape* their experiences through drug use:

Excerpt: Nick 8:

“I escaped my inner fears from smoking, I escaped what was happening to me, well, I escaped what I didn’t want to acknowledge was happening, I guess”.

For a period after diagnosis, Beth 2, Daisy 5, Tamsin 9 and Debbie 3 continued to conceal their diagnosis and difficulties from family and friends.

Excerpt: Debbie 3

“I was managing a job, I was managing college, I was managing secret hospital appointments, and I was on medication, and I was getting counselling and my family had no idea”.

Excerpt: Beth 2

TP: So once you were in hospital, once you’d gone through that experience, did you then feel you could talk to people about it, or was it something you still felt like ‘no, I need to keep this to myself?’.

“No, I kept it to myself, it’s something I’m a bit embarrassed about. I felt almost like having been to hospital was a bit selfish, somehow”.

Negative cases

Although Daniel 1 described getting into vicious cycles of unhelpful behaviour during the onset of his difficulties, he was the only participant who did not refer to getting stuck in maladaptive patterns of coping after his hospital admission. However, he was the first participant to be interviewed and therefore was not specifically asked about this.

5.1.7 Moving on

The last category to emerge from participants’ experiences was *moving on*. Experiences relating to this category did not feature in every participants account, indicating that some participants were at different stages in terms of their recovery. Although some of these subcategories are not as well populated as others, it was nonetheless an important category to present, particularly given the fact that the analysis was structured in a sequential way, following the experience of psychosis in stages. Those participants whose narratives contributed to this category spoke of experiences relating to *growing through it, strengthened relationships, acceptance and ingredients for recovery*.

Participants whose experiences contributed to this category were Daniel 1, Beth 2, Debbie 3, Steven 4, Nick 8, Tamsin 9 and Abbie 10.

5.1.7.1 Growing through it

Four participants (Daniel 1, Debbie 3, Steven 4 and Nick 8) described their experiences as formative, and talked about perceived benefits. This is best captured by the following exemplar:

Excerpt: Nick 8:

“Its really funny I mean, after through everything, through all this crap that I’ve been through I’m in a better place. I actually feel that I wouldn’t be the person I am today if it wasn’t for these things that have happened to me”.

5.1.7.2 Strengthened relationships

Two participants (Daniel 1 and Debbie 3) spoke of how their relationships with family and friends had strengthened as a result of their experiences:

“Like, my relationship with him has grown as a result, as well as my relationship with my parents”.

TP: “Tell me about that then. How have your relationships changed?”.

“I’m much more closer, because I’ve been through this with my friends, with my family, my brother, my new friends actually (...) I mean, people gravitate towards me now and they’d never gravitate towards me before this experience”.

5.1.7.3 Acceptance

Four participants described reaching a position of acceptance in relation to their illness and its consequences; something which appeared to be key in terms of beginning to recover:

Excerpt: Debbie 3:

*“... you do lose people and you kind of have to cut your losses and think well if they weren’t willing to stick through that then f**k them, pardon the swearing (...) You have to kind of realistically know your limits and try not to over exceed them and try to work with you’ve got and then things will improve”.*

5.1.7.4 Ingredients for recovery

Six participants spoke about what they considered to be the ‘ingredients’ for recovery. Key themes related to *normalising experiences, developing new relationships, social acceptance and confiding in others.*

5.1.7.4.1 Normalising experiences

Six participants (Daniel 1, Beth 2, Debbie 3, Nick 8, Tamsin 9 and Abbie 10) spoke of how important normalising experiences had been in terms of their adaptation and recovery from psychosis. This is illustrated by the following exemplar:

Excerpt: Abbie 10

“... when I went to the doctors and they said, you’re not weird or anything, you’re not a freak, and we can help you, I started feeling like maybe I could tell them, but I’d left school by this time and I hadn’t talked to them in about six months. So I called up my friend one day and she was like how come we haven’t heard, and I was like I’ve been getting help and that, and she said I’m sorry I couldn’t have been there to help you and that and that just made me feel better”.

5.1.7.4.2 Developing new relationships

Four participants (Daniel 1, Beth 2, Debbie 3 and Tamsin 9) described their sense that developing new relationships had contributed positively to their recovery:

Excerpt: Tamsin 9

“... but now that I have a boyfriend I’m quite a lot happier”.

TP: How has that changed things for you?

“Just somebody liking you, it feels good. It’s made me go softer, and silly, and not as rough”.

5.1.7.4.3 Social acceptance

The importance of social acceptance in terms of moving on was a key theme in four participants’ narratives (Beth 2, Debbie 3, Tamsin 9, and Nick 8), as illustrated by the following exemplar:

Excerpt: Tamsin 9

“Going back to school has been very helpful. Like, people were asking for me, like, saying ‘why weren’t you in school?’ and although I was worried about it I told them I had psychosis ‘cause that’s what EPSS had told me to do”

TP: What were people’s reactions like?

“Much better than I expected. People weren’t like ‘oh my god you have psychosis’, they were more, just, interested”.

5.1.7.4.4 Confiding in others

The perceived benefits of talking to family, friends and professionals about these difficult experiences formed a key theme in participants’ narratives of recovery, as captured by the following exemplar:

Excerpt: Nick 8

“Like it made me feel so good to actually talk to people about it and like release it, and eventually that helped me to built up the confidence to go to CAMHS and get some counselling and stuff”.

TP: And has that experience of going to CAMHS figured at all in terms of recovery?

“It’s helped. To be able to talk to professionals about it, and to almost say, and for them to explain that, like I know other people have problems and stuff, but to hear it from somebody else makes you feel better, it really does” .

It is noteworthy that those participants whose experiences contributed more fully to the development of this category (Daniel 1, Nick 8, Debbie 3 and Tamsin 9) also had the highest scores on the QPR, indicating that they were at a more advanced stage of recovery than some of the other participants.

6. Interpretation and discussion

This section will highlight the key concepts and processes identified above and consider these findings in the light of existing literature. A summary of the grounded theory to emerge from this research will then be presented, along with the proposed model illustrating the hypothesised experience of depression and anxiety in adolescents developing psychosis. This will be followed with a consideration of clinical implications, areas for future research and strengths and limitations of the current study.

In keeping with current literature (Iqbal *et al.*, 2000; Birchwood *et al.*, 2006), social anxiety and in particular, depression, were highly prevalent in the experiences of these young people. All participants were clinically depressed according to the CDSS in the two weeks prior to onset of psychotic symptoms (Table 2). A concerning finding was the frequency of suicidal ideation and intent experienced by these young people. Five of the participants had made at least one attempt to end their life and four had made several attempts. The remaining participant spoke about experiencing suicidal ideation following relapse but she had not made an attempt to end her life. Whilst acknowledging that the limited sample in this study may not be reflective of the population, this finding suggests an alarming prevalence of suicidal behaviour, which appears to exceed that of recent existing studies. For example, Falcone *et al.*, (2010) report a 32 per cent incidence of suicide attempts in this cohort and, in keeping with the current study, found that depressive symptoms were significantly correlated with increased suicide attempts.

Arguably the most consistent theme to emerge from participants' narratives was isolation. What was striking was how many of the experiences narrated by participants led to them become isolated, and how isolation was experienced as linked to depression, anxiety and psychotic symptoms (as captured by researcher memo 'All roads lead to isolation', Appendix 6). Eight of the nine participants appear to have been experiencing significant depressive symptoms prior to the onset of psychotic symptoms, according to pre diagnosis scores on the CDSS. It may well be that at this stage of the illness depression emerged in relation to isolation as all of these participants described experiencing increasing social withdrawal and self isolation at this time. Isolation has long been recognised as a risk factor for the development of psychotic illness (Kohn & Klausen, 1955). In typical adolescent development, teenagers generally progress through a same sex friendship group to a mixed sex group followed by the formation of 'romantic dyads' (Brown *et al.*, 1986). However,

individuals with psychosis tend to have significantly smaller social networks, with fewer friends, fewer people to whom they can turn in a crisis and limited romantic relationships (Macdonald *et al.*, 2000). What was interesting about these findings was that, whilst this was true of some participants, others described having a good network of friends prior to the onset of psychosis but choosing to engage with them less as their problems developed. For them, isolation did not stem from limited opportunities for social interaction or from anxiety about being around others, at least initially. Rather, they described something *functional* for them about stepping back from others, e.g. 'Being alone helps me to cope with difficult feelings.'; '...means that I won't worry anyone'; '...helps me to feel safer', etc.

Meng *et al.*, (2006) examined the predictive validity of pre-treatment social functioning on symptomatic and functional outcome in adolescents. Their findings suggested a strong longitudinal interrelatedness between social functioning and negative symptoms in adolescents with first episode psychosis. What the current findings add is the notion that isolation, caused by various maladaptive efforts to cope with deteriorating mental health, may mediate this relationship, and that isolative behaviour often begins through choice initially, rather than solely as a result of social circumstance.

Unfortunately, as these participants were able to recognise in retrospect, this choice to withdraw had negative consequences, in that it initiated a vicious cycle of low mood, anxiety and later, psychotic experiences. This finding links into research by Garety *et al.*, (2001) who purport that social isolation provides a facilitative environment for the development and maintenance of delusional ideas. One hypothesised pathway is that social isolation facilitates more ready acceptance of the psychotic appraisal by reducing access to alternative, more normalising explanations (White *et al.*, 2000).

Central to all of the participants' narratives were maladaptive coping and mood regulation strategies, clustering around attempts to escape the experience or vicious cycles of behaviour. Again, the critical outcome resulting from these processes was isolation. Whilst isolation is a well observed factor for individuals during the prodrome, it is important to note that in this group of young people, these same processes occurred both during the prodrome and the adaptation phase, contributing to a sense of 'getting stuck' in psychosis. Essentially, similar cycles opened up again during the adaptation phase and contributed to a failure to adapt to the experience for many.

The theme of escape was common in most participants' experience. Young people clearly described using drugs as a means of escaping what they perceived to be unbearable emotions (e.g. grief, anxiety), in addition to escaping the experience of psychotic phenomena. The findings relating to coping have potential relevance to several areas of literature. Firstly, the concept of 'recovery style' (McGlashan, *et al.*, 1977), and the related notion of a 'sealing over' coping style, whereby a person copes by minimising the significance of symptoms and the impact of psychosis on their life, and by taking a disinterested stance towards the experience. An 'integration' coping style, by contrast, describes a process whereby a person acknowledges the importance of their psychosis, bears its painful aspects, is curious about it and relinquishes their attempt to "go it alone" (McGlashan *et al.*, 1975). A young person using escape as a means of coping indicates that they may be attempting to 'seal over' their experience.

The current findings relating to coping strategies are also consistent with research findings from Yanos *et al.*, (2008), who investigated the mechanisms by which internalised stigma affects outcomes. They found that internalised stigma leads to increased avoidant coping, active social avoidance and depression. The relationship between these factors was shown to be mediated by the impact of internalised stigma on hope and self esteem. It is possible that the participants in this study had high levels of internalised stigma and that this contributed, at least in part, to their maladaptive coping strategies.

Another significant finding to emerge related to the fact that consistently, young people attempted to cope alone with their deteriorating mental health. This has clear links with literature regarding duration of untreated psychosis (DUP). Research suggests that periods of initially untreated psychosis result in poorer outcome and greater vulnerability to future relapse (Norman & Malla, 2001). A longer episode of untreated psychosis is also associated with more severe depression and anxiety at initial presentation in addition to more severe psychotic symptoms (Marshall *et al.*, 2005). Although much attention has been paid to outcome in relation to DUP, relatively less research has considered what delays presentation.

Longer DUP has been shown to be associated with insidious onset of psychosis (Morgan *et al.*, 2006) and predicted by poor social integration (Drake *et al.*, 2000) but the specific reasons for this are unclear. The findings from this study add to the literature base, in providing a psychological explanation for *why* young people with psychosis are so difficult to engage and why duration of untreated psychosis can be so long: fear of stigma; fear of

hospitalisation; anticipated rejection and concern about being labelled. Mistrust, due to previous experiences of being let down was also cited as a reason for not disclosing these experiences.

What was clear from participants' accounts was the significance of what they had experienced and the difficulties of adaptation. As detailed in systematic literature review, Birchwood *et al.*, (1993) conceptualise psychotic illness as an apparently uncontrollable life event, and propose that depression following psychosis arises due to psychological appraisals about the illness, particularly relating to beliefs about lack of control over the illness ('entrapment') and appraisals of loss of autonomy and social role (Rooke & Birchwood, 1998). These findings have since been replicated (Iqbal *et al.*, 2000) and the concept of 'humiliation' relating to the illness, has also been associated with the development of depression. Certainly, the findings from the current study would support these hypotheses. Several participants spoke about their experience of 'dropping into depression'; something which was experienced as directly related to specific psychological appraisals about the meaning or significance of their psychotic experiences. These appraisals included: loss of hope for the future, loss of control over life, and; a sense of having missed out on 'normal' life and experience. The current findings also add to these hypotheses, by highlighting appraisals about loss of identity as another potential mediator between psychosis and depression.

In their conceptual model of positive outcomes and of life crises and transitions, Schaefer & Moos (1992), outline factors which determine positive outcomes of crises. In a similar vein to Birchwood's (1993) conceptualisation of psychosis as an uncontrollable life event, the experience of psychosis could also be conceptualised as a life crisis. Schaefer & Moos (1992) tenet that environmental and personal factors shape both the experience of the crisis and the cognitive appraisals and coping responses initiated thereafter, and that these, in turn, affect the outcome of the crisis. The personal 'system' includes personal resources such as optimism, self efficacy, motivation and self confidence and prior crisis experience. Important aspects of the environmental system are personal relationships and family support. They propose that all aspects of the model are linked by feedback loops, thus influencing one another. Viewing the current findings within their conceptual framework goes some way to explaining why the outcome of psychotic illness is often less than favourable. The vast majority of the young people in this study had gone through experiences which could be defined as 'life crises' (loss, abuse, etc) prior to onset of psychosis and described

withdrawing from relationships and potential sources of support as their mental health deteriorated. Experiences of relapse or unremitting psychotic and/ or affective symptoms negatively impacted participants' sense of hope, confidence and self-efficacy. According to Schaefer & Moos' (1992) model, these factors would shape both the experience and outcome of psychosis in an unfavourable way. What the current findings add to this conceptualisation is the key role that affective states also appear to have on the outcome of adaptation to this kind of life crisis.

What was particularly striking about these findings was the clear description of reciprocity between low mood, anxiety, isolation and psychotic experiences. This relationship appears to be central to the young person experiencing psychosis, and to the failure to adapt and recover from psychosis in some cases. Most participants reported a bi-directional relationship between their experience of psychotic symptoms and low mood:

Excerpt: Abbie 10

“Erm, when I was low I was paranoid, and when I was paranoid it made me feel even more low. And it was kind of like you said, like a vicious cycle”.

Several participants noted that they were more likely to experience auditory hallucinations when their mood was low, and others described how hallucinatory experiences became more powerful and distressing when they were depressed:

Excerpt: Nick 8

“... [the voice is] this alternate persona which just kind of feeds on when I am down (...) I would be sitting there and I would be in a mood, and I would be really upset, he would all of a sudden pop up, and he would start nagging me”.

Excerpt: Abbie 10

“I'd been hearing voices like before he died, but they didn't start saying horrible things until after he died, when I was feeling really depressed”.

These findings are in keeping with current literature. Smith *et al.*, (2006) found that individuals with lower mood and lower self esteem have auditory hallucinations of greater severity and more intensely negative content and are more distressed by them. The findings from this study provide support for their hypothesis that the direction of the relationship

between auditory hallucinations and low mood is driven both by the voices and the negative affect that results.

An interesting theme which emerged was the ‘fear of being found out’, i.e. a strong fear that people will find out about their illness and react negatively towards them as a result. Participants described how this experience led them to feel socially anxious and avoidant of others. These findings tie in with research investigating the impact of perceived stigma on social adaptation (Perlick *et al.*, 2001), which found that concerns about perceived stigma predicted higher avoidance of social interactions with persons outside the family in addition to psychological isolation at seven month follow-up, even after controlling for symptom severity, baseline social adaptation and socio-demographic factors. Whilst this process was certainly at play for several participants, interestingly, the current findings also suggest that ‘corrective’ social experiences, i.e. experiences where others are accepting of the young person and their difficulties, can break the cycle of social avoidance and play a role in the young person beginning to recover.

In addition to fear related to anticipated stigma, the experience of actual stigma was unfortunately part of some young people’s experience and was linked to the development of low mood and suicidal ideation. Markowitz (1998) examined the relationship between stigma, psychological well being, and life satisfaction in a large sample of outpatients. The experience of stigma was found to be related to depressive/ anxiety type symptoms but not psychotic symptoms. In keeping with this, the current findings indicate a clear relationship between the experience of stigma and the onset of low mood and anxiety. What they also suggest is that whilst stigmatising experiences may not directly influence psychotic symptoms, they may do so indirectly due to the apparent relationship between affect and psychotic phenomena described by participants.

The concept of growing through and in some way benefitting from the experience was another theme to emerge and seems to be allied to concept of *resilience*, which has been used to refer to personal growth after the experience of serious negative life events (Schaefer & Moos, 2001). It may also bear relevance to an element of the concept ‘positive reappraisal’, whereby ‘an individual is able to negotiate the appraisal of stressful life circumstances so that they are less negative or even positive’ (Roe *et al.*, 2006 p. 7).

An emergent theme related to recovery was the notion of acceptance of illness and the consequences which have resulted from it. There seem to be some parallels here with the

rationale underpinning Acceptance and Commitment Therapy (ACT; Hayes *et al.*, 1999), a therapeutic approach which, unlike other approaches which emphasise frequency, veracity and irrationality of symptoms, targets the individual's *relationship* to those events. ACT seeks the development of new responses in the presence of a previously avoided event. What is clear in the current study is that several participants were able to shift their perspective in a way which is akin to the process underlined by ACT. What is less clear are the specific factors which helped them to do this.

6.1. Summary of grounded theory

The model in Figure 2 represents a grounded theory of the experience of and relationship between psychosis, depression and anxiety. It illustrates the links between some of the key concepts and processes which emerged from the interviews and elucidates the processes that may be involved in young people's experience of psychosis and affective disturbance. As such, it can be considered a process model. As a caveat, it should be noted that the proposed model has emerged through the researcher's interpretation of participants' accounts of experiences of psychosis and is, therefore, tentative; requiring further research to validate the proposed processes.

During the onset of psychosis, in making attempts to cope with changes to their mood and developing psychotic phenomena, young people get stuck in vicious cycles of behaviour which lead them to become isolated from others and cope alone with these experiences [1]. These vicious cycles are motivated by fear of consequences (hospitalisation, medication), mistrust of others and fear of anticipated rejection. In addition, they frequently make attempts to escape from these experiences through self isolation, the use of drugs, truanting, self harm and suicide attempts [2]. These processes of maladaptive coping and poor mood regulation lead to increasing isolation [3], which is then linked to the development of depression [4] and social anxiety [5], both of which aid the development of psychosis. The more isolated, depressed and anxious the young person feels, the more omnipotent and distressing the hallucinatory experiences and delusional beliefs become [6] and the more anxious and low they feel.

At some point, young people are no longer able to contain their experiences and they reach 'breaking point' [7]. At this stage, help is mobilised, either because the young person makes a suicide attempt, breaks down and discloses their experiences to someone, or their psychotic symptoms become obvious to others.

The young person then faces the task of adaptation [8], whereby the same patterns of maladaptive coping (escape and vicious cycles) open up, functionally ‘trapping’ the young person [9] and hindering adaptation to the experience. The experience of continued psychotic symptoms in some young people elicits feelings of depression and anxiety, as does the fear of their illness being ‘found out’ by others [10]. In addition, during this process, young people evaluate the impact of the illness on their life and experience feelings of loss (of hope, control, identity, aspired future self, friendships) and perceived and actual stigma, which further contribute to experiences of low mood and anxiety [11].

Several experiences facilitate a young person to begin moving on from this ‘trapped’ position. Experiences of normalisation, through contact with a service or meeting other people with similar problems, confiding in others and experiencing social acceptance of their diagnosis/ difficulties are key [12]. Likewise, developing new relationships, beginning a process of acceptance of what the experiences have entailed and, latterly, recognising any benefits that have emerged as a result of the experience [13] contribute to the process of recovery [14].

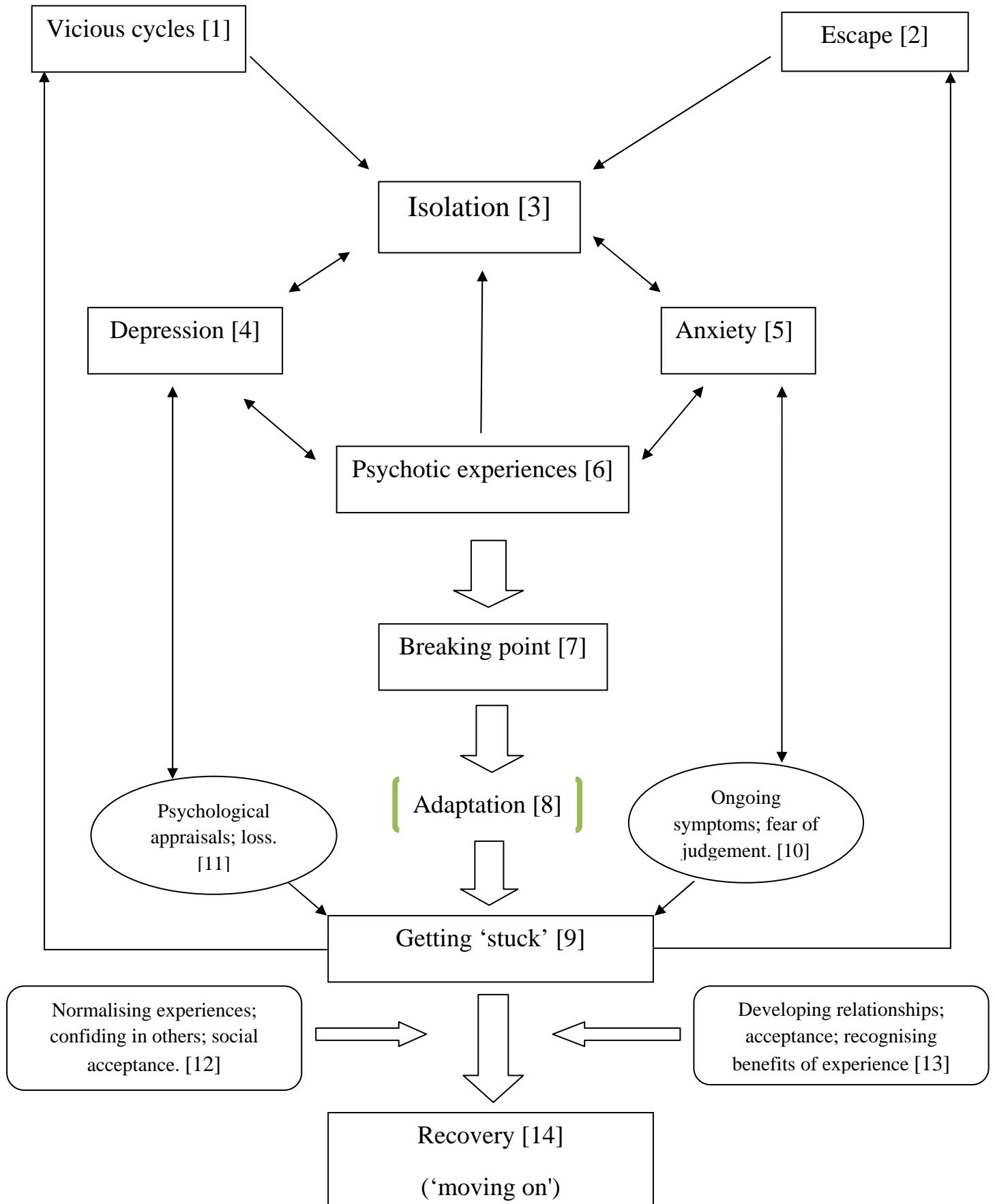
6.2. Preliminary hypotheses

The findings from this study suggest that depression and anxiety are not co-morbid features of psychosis, but are intrinsically linked to the underlying processes involved in coping with and adapting to psychosis. Maladaptive coping and mood regulation strategies are represented throughout this process and it is these that appear to be linked to the manifestation of depression and anxiety, partly mediated by isolation. This is demonstrated by the fact that these processes are active in the onset and origin of psychosis, as well as the adaptation to psychosis and recovery stage.

The proposed model and hypothesis provide a rationale for why depression and anxiety are so prevalent and why they manifest at various stages of the illness (Iqbal *et al.*, 2000), because the processes which appear to lead to their manifestation recur at various stages.

In the light of the current findings, one could speculate that people who are at risk of psychosis and who manage to come out of these vicious cycles, share experiences, and receive normalising, corrective information may not go on to develop psychosis or may be able to recover more quickly.

Figure 2: A grounded theory of the experience of depression and anxiety in adolescents developing psychosis



6.3. Clinical implications

What emerged as key in this study was young people's experience of psychosis as one which was intrinsically experienced and described in relation to others. The findings support a psycho-developmental account, which implies that therapeutic priority should be given to re-establishing the young person's links with their peer group, through strategies such as work placement schemes, peer group activities, etc (Harrop, 2002). Young people's experience of social acceptance appeared to be 'corrective', i.e. a factor which facilitated them beginning to recover.

These findings also support the move away from a symptom based approach, to an interpersonal approach. The question for clinicians and researcher alike is: 'how can these young people be around other people, develop meaningful relationships and learn to communicate their experiences?'.

The current findings raise the interesting question of how useful the clinical labels 'depression' and 'social anxiety' are in this particular context. Whilst the psychological literature focuses on these two terms, used to denote specific kinds of *experiences*, it could be argued that their use in this context deflects attention from the *processes* which contribute to their development. It could be argued that substituting these terms with 'emotions/ beliefs/ behaviours that lead to isolation', may be more useful (and perhaps more normalising) in terms of understanding these processes and working therapeutically to reduce them.

During recent years, increasing evidence about delays in accessing services being significantly associated with poorer outcome, has led to the importance of intervening as early as possible in first episode psychosis becoming internationally accepted (Lester *et al.*, 2009). Clearly, the current findings lend support to the early intervention movement, indicating that much of the change underpinning the development of the acute illness appears to be active in the prodromal phase. Therefore, in accordance with Birchwood & Macmillan (1993), this pre-psychotic stage may well be a particularly sensitive phase of the "critical period". However, this conjecture does not bypass the problem that young people, it would seem, are actively avoiding help seeking at this point, due to fear of hospitalisation and/ or medication and concern about having a label 'attached' to them. The commonality of these experiences in the current findings indicates strongly that young people are not receiving normalising information about psychosis and that societal stigma about the illness prevails. Services need to give young people 'permission' to disclose their experiences. At a wider

level, young people would benefit from high profile national educational campaigns about psychosis, clearly communicating the message that we understand reasons why young people are fearful to access services but that the sooner they receive support the easier things will become. Considering the detrimental impact that choosing to cope alone apparently has on young people's mental health and the related risk of suicide, efforts to remedy this on a national level should be a priority.

These young people are clearly communicating the benefit in terms of recovery in receiving corrective, normalising information about psychosis and this should therefore be a focus of therapeutic intervention. These findings indicate a need to pay greater attention in therapy to concerns about stigma, due to its apparent association with depression, anxiety and social avoidance.

The apparent reciprocity between isolation, depression, anxiety and psychotic experiences support the assertion by Garety *et al.*, (2000, p. 74) that: 'the hypothesised role of emotional processes such as depression and anxiety in the maintenance and onset of psychosis leads to the direct application of cognitive therapy techniques for these problems'.

Lastly, there is some evidence that the use of cannabis may bring forward the onset of psychosis in a vulnerable individual (Hambrecht & Hafner, 1996). The high prevalence of substance abuse (40 per cent) in these young people ties in with current research (Mastrigt *et al.*, 2006), although determining the direction of causality has been difficult. The current findings lend support to the notion that drugs, in particular cannabis, are used both as a means of coping pre psychosis, and as a way of managing symptoms following the first episode of psychosis. This clearly has implications for outcome and treatment; suggesting that substance misuse should be addressed as a priority from the very beginning.

6.3. Strengths of the study

To the author's knowledge, this study is the first to investigate the subjective experience of depression and social anxiety in young people with psychosis and to preliminarily identify the psychological processes underlying the relationship between these experiences. The use of mixed-methods added triangulation to the findings.

This research has provided an insight into the lived experiences of young people who have experienced a first episode of psychosis, allowing for emerging themes to be considered in relation to existing literature. The findings add to the limited literature base of child and

adolescent psychosis research and identify preliminary hypotheses about the experience of and relationship between psychosis, depression and anxiety in young people. This research has taken a step towards understanding patterns of behaviour that young people tend to adopt during the prodromal phase, the reasons *why* these manifest and how these patterns link to the experience of low mood, anxiety and psychosis.

6.4. Limitations of the study

Given the constraints posed by limited time and resources, the current study has some methodological and conceptual limitations.

The scale of this research did not allow for full realization of the concepts of theoretical sampling and saturation. It is likely that further interviews would have led to further refinement of categories and subcategories and possible that new categories may have emerged from this process.

A second limitation relates to the use of CDSS as a measure of depression in the pre-psychotic stage (i.e. retrospectively). Two issues arise from this. Firstly, the CDSS was not designed to assess depression retrospectively and therefore has not been validated for use in this way. Secondly, this leads to the potential for recall bias and therefore may not accurately reflect the depressive experiences of the participants at this stage.

Thirdly, in theory, the grounded theory researcher should be naive to the research topic to prevent the likelihood of any pre-specified hypotheses influencing data collection and analysis. In practice, however this is not always possible and often, as is the case here, the researcher works in the area of inquiry. As previously described, researcher reflexivity goes some way to resolve this predicament (Charmaz, 2006) and is a key process in producing reliable findings in grounded theory research.

In larger scale research, another method of validation often undertaken is re-interviewing participants in order to clarify initial findings and/ or allow participants to review and amend the transcripts and coding structure. Due to constraints on time and a concern at the design stage that this may negatively impact on participants' willingness to engage, this method was not included. Future research might benefit from this type of triangulation. In addition, it is likely that this study would have benefitted from cross-validation through multiple coding by various researchers.

It is possible that the sampling method may have introduced an element of bias, as those participants who were invited to take part but declined may have differed in important characteristics from those who participated.

The research timescale and practical constraints of recruiting participants dictated a relatively small sample. Whilst 8-10 participants are common numbers in grounded theory projects of this size, a more substantial sample may have been preferable. However, the aim of the research was to propose initial hypotheses towards a developing theory which might merit subsequent validation through further research, as opposed to the unrealistic intention of producing a more fully developed theory.

6.5. Future research

In terms of the current findings, future research might focus more on the experience of ‘moving on’, in particular, an exploration of what contributes to the apparent shift in young people’s appraisals between the ‘getting stuck’ and ‘moving on’ stages, whereby appraisals change from those of loss, shame, etc. to perceived benefits of the experience.

An interesting area for future research would be to consider the current findings in light of attachment theory (Bowlby, 1969), which has been used as a framework to explain the link between emotional distress and help-seeking, or lack thereof. For example, research indicates that maladaptive attachment experiences are linked with a ruminative or avoidant style of dealing with unexplained and distressing internal experiences (Gumley & Schwannauer, 2006) and it is possible that this has relevance to the current findings.

An interesting finding in this study was that those participants who used drugs as a means of escaping their difficulties were all male. Clearly, in a sample of this size it is impossible to make any inferences towards this cohort as a whole, but this is in keeping with the literature (Mastrigt *et al.*, 2006). An interesting avenue for future research would be investigation into why males are more likely than females to rely on this particular avoidant strategy.

6.6. Summary and conclusions

The current study explored the experience of and the relationship between psychosis, depression and anxiety in young people. The overarching theme to emerge was that of the experience of a developmental trajectory of psychosis. In line with current literature, findings indicated that depression, social anxiety and suicidal behaviour are common young people

who have experienced a first episode of psychosis. These experiences appear to be intrinsically linked to underlying processes related to coping and adaptation to psychosis, rather than representing 'true' co-morbidity. Isolation, low mood and anxiety were universal outcomes and appeared to be mediated by maladaptive forms of coping and mood regulation (vicious cycles and attempts to escape) in addition to psychological appraisals during the pre-psychotic stage as well as the adaptation and recovery phases. This research argues for the central role of isolation in the relationship between psychosis, depression and anxiety and strongly suggests reciprocity in the relationship between these factors. The findings shed further light on why some people fail to adapt to and recover from psychotic illness and why psychotic illness can be so debilitating. The preliminary model (Figure 2) and hypotheses generated by this research offer some insights relating to the variability in onset and course of depression and anxiety in people with psychotic illness. However, further research is needed to develop these findings. Given the evidence on outcome and risk of suicide for young people with adolescent onset psychosis, research in this area should be a priority.

7. Journal article

Title

A grounded theory of the experience of depression and social anxiety in young people developing psychosis.

Abstract

Young people recovering from first episode psychosis experience a high degree of emotional distress and co-morbidity. Depression and social anxiety are highly prevalent following first episode psychosis and have been associated with poorer outcome, increased risk of suicide and lower quality of life. However, there is little research examining how these emotional difficulties relate to the course of psychotic symptoms and subsequent adaptation and recovery. The primary aim of this research was to establish a grounded theory of the experience of mood and anxiety related difficulties in young people who experience a first episode psychosis. Secondly, the research aimed to establish the underlying psychological factors contributing to the relationship between psychosis and affective dysfunction. The study used a social constructivist version of grounded theory to develop an experiential account of psychosis, depression and social anxiety. Ten young people who had experienced first-episode psychosis were interviewed about their experiences and interviews were transcribed and analysed using a social constructivist version of grounded theory. The overarching theme to emerge was *the experience of a developmental trajectory of psychosis*. Seven key categories were identified. *The build up; coping; breaking point; facing diagnosis; impact of illness; getting stuck and; moving on*. Isolation, low mood and anxiety were universal outcomes and appeared to be mediated by maladaptive forms of coping and mood regulation in addition to psychological appraisals and negative illness related experiences such as stigma and loss. The findings suggest that depression and anxiety are not co-morbid features of psychosis, but are intrinsically linked to the underlying processes involved in coping with and adapting to psychosis. Implications for clinical practice and further research are reviewed.

Keywords: Psychosis; schizophrenia; depression; social anxiety; adolescents; grounded theory.

7.1. Introduction

Psychotic illness affects 3.4 per cent of the population over a lifetime (Perela *et al.*, 2007) and 80 per cent of first episodes of psychosis emerge between the ages of 16 and 30 years (Lester *et al.*, 2009). It is estimated that approximately 200,000 adolescents in Edinburgh, the Lothians, Lanarkshire and South Glasgow are at risk of developing psychosis (Compton, 2001).

Psychosis can have a devastating and wide-reaching impact on a young person's functioning and carries a high risk of suicide (approximately 7 per cent), with the highest risk found during the first years of treatment (Palmer *et al.*, 2005). Research suggests that the consequences of adolescent onset schizophrenia are more severe than those of adult onset schizophrenia, with poorer social adjustment, severe functional impairment and high socioeconomic dependence (Lay *et al.*, 2000; Malla & Payne, 2005). In addition, individuals who have onset of psychosis in adolescence tend to have significantly longer duration of untreated psychosis (DUP) (Ballageer *et al.*, 2005). This concept has attracted considerable interest and a number of studies suggest a significant relationship between longer DUP and poorer clinical and functional outcome (Malla & Payne, 2005).

People with psychosis experience a high degree of co-morbidity and report significant emotional distress. Depression occurs in 80 per cent of patients at one or more phases of first-episode psychosis and is associated with acts of deliberate self harm and suicidal thinking (Upthegrove *et al.*, 2010). Indeed, the prevalence of suicidal behaviour during the early phase of psychosis has been shown to rise in parallel with the severity of depressive symptomatology (Gonzalez-Pinto *et al.*, 2007). Furthermore, depression predicts poorer outcome, including more frequent psychotic relapses and hospitalisations and poorer quality of life (Buckley *et al.*, 2008). Upthegrove (2009) reviewed the literature on depression in psychotic illness and concluded that whilst there appear to be different mechanisms involved at different phases of the illness, currently there are no clear answers about the underlying causes of depression in this group.

Social anxiety is also common following psychosis. In the first year following onset of psychosis, 29 per cent of individuals report symptoms which meet diagnostic criteria for social anxiety disorder (Birchwood *et al.*, 2006). A further 11.6 per cent report clear difficulties in social interaction and/ or signs of avoidance which are not sufficient to fulfil formal diagnostic criteria (Michail & Birchwood, 2009). This co-morbid diagnosis has been

found in 36 per cent of outpatients and is associated with a higher lifetime rate and greater lethality of suicide attempts and lower quality of life (Pallanti *et al.*, 2004). Research suggests that social anxiety is not just an epiphenomenon of psychotic symptomatology and paranoia and that it appears to have more than one causal pathway (Michail & Birchwood, 2009), although, as yet, those pathways remain far from clear. What is clear, however, is that the experience of depression and social anxiety during recovery from first-episode psychosis has clear implications for a person's ability to adapt to the experience and to reintegrate socially and vocationally.

The vast majority of research on psychotic illness relies on adult populations, many of whom have chronic schizophrenia, and there is a distinct absence of research considering the experience of anxiety and depression in young people who have experienced first episode psychosis. Hollis (2003, p. 37) has warned against the dangers of 'slavishly applying' research findings from adult samples to children and adolescents; something that too frequently happens due to the paucity of research with this group. Findings from adult populations indicate that in the context of psychosis, these affective disturbances have clear implications in terms of a young person's ability to adapt to the experience and to reintegrate socially and vocationally, not to mention the risk of suicide. However, the nature and origins of depression and social anxiety in psychosis are very poorly understood at present and further knowledge about this relationship is urgently needed.

7.2. Aims of research

The primary aim of this research was to establish a grounded theory of the experience of low mood and anxiety related difficulties in young people who experience a first episode psychosis. Secondly, the research aimed to establish the underlying psychological factors contributing to the relationship between psychosis and mood and anxiety difficulties.

7.3. Method

The method used in this study was a social constructivist version of grounded theory which emphasises the role of the researcher as an active agent in the co-construction of the narrative, meaning making process and the interpretation of these narratives. The emergent

theory is therefore a context-dependent interpretation of the data made by the researcher (Charmaz, 2006).

7.3.1 Theoretical background

A qualitative methodology was adopted for several reasons. Firstly, there is a paucity of research examining the experience of affective dysfunction in adolescents experiencing a first episode of psychosis and this lends itself well to qualitative exploration. Secondly, the meanings and concepts ingrained in individual narratives of the experience of psychosis, depression and anxiety may not have been delineated by the current literature.

7.3.2 Ensuring rigour and quality

In order to promote reliability and validity of the data, the researcher adopted the four flexible and open-ended principles proposed by Yardley (2000): 1) sensitivity to context; 2) commitment and rigour; 3) transparency and coherence and; 4) impact and importance.

To increase methodological rigour, the initial coding structure and strategies for coding were reviewed by two colleagues who were experienced in qualitative research methods.

7.3.3 Sensitivity to context

The Early Psychosis Support Service (EPSS) is an early intervention service for young people with psychosis aged between 12-19 years. EPSS sits within a Tier IV Child & Adolescent Mental Health Service (CAMHS). The service provides intensive intervention during the three year 'critical period' following the first onset of psychosis. EPSS provides a recovery-based approach with the aim of minimising or preventing many of the secondary personal, social and occupational disabilities which typically develop following a psychotic episode. EPSS has an assertive outreach approach to engaging with young people and wherever possible, aims to avoid a young person's admission to hospital.

7.3.4 Reflexivity

An important concept in grounded theory research is reflexivity, defined by Charmaz (2006, p. 188-189) as:

‘The researcher’s scrutiny of his or her research experience, decisions and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher’s interest, position and assumptions influenced inquiry’.

The researcher in this study was a trainee clinical psychologist working in a young people’s inpatient unit within Tier IV CAMHS. In keeping with the researcher’s ontological and epistemological stance of ‘critical realism’ (Bhaskar, 1989), she acknowledged that her own perspective would influence both her interactions with those she interviewed and her subsequent data analysis. She did not have personal experience of psychosis but had some experience of working clinically with young people and adults with psychosis, both during her training and prior to this as an assistant psychologist.

7.3.5 Data collection

Interviews were in-depth, open-ended and unstructured, with an evolving focus. This style of interviewing and the absence of a set agenda/ interview schedule was chosen with the aim of promoting engagement and facilitating collaboration between the interviewer and interviewee. Emphasis was given to creating an environment which felt safe for the young people to tell their story and reflect on their experiences. All interviews were opened in the same way, ‘I’m interested in hearing about your experiences that led you to come into contact with EPSS and how they have affected you as a person’, and followed up with relevant prompts, e.g. ‘What was that like for you?’. In order to tap into specific autobiographical memories, the researcher asked ‘Tell me about a particular time that stands out in your memory?’.

7.3.6 Participants

Potential participants were identified by the EPSS multi-disciplinary team during their weekly meeting. The capacity of each young person to take part was assessed by their Responsible Medical Officer (RMO). Participants were required to have been in active treatment at EPSS for at least three months.

The 10 young people who participated in the study were between the ages of 14 and 19 (median age 17 years 3 months). Five of them were male. Participants’ diagnoses fell within the spectrum of psychotic disorders, including early onset psychosis, psychotic depression, bi-polar disorder and puerperal psychosis. Demographic information can be found in Table 1.

Table 1: Demographic information for participant sample

Demographic information	Number of participants N=10
Sex	5 male 5 female
Age	14 -19 years (median 17 years 3 months)
Ethnicity	9 White Scottish 1 Chinese
Living situation	8 living with parents 1 living in a residential unit 1 living alone
Age first CAMHS involvement	3 - 17 years (mean 6 years 9 months)
Age first Psychosis Service contact	14- 18 (mean 16 years 6 months)
Admissions	4 no admission, 4 one admission, 1 two admissions, 1 three admissions

7.3.7. Procedure

Ethical approval for the study was gained from the South East Scotland Regional Ethics Committee 03 (REC reference 11/AL/0019). Participants were informed about the study and invited to participate by their key worker, who provided them with a participant information sheet. Upon agreeing to take part, they were asked to sign a consent form. All interviews were recorded and transcribed by the researcher. Interview length ranged from 29 minutes to 1 hour and 25 minutes (median=57 minutes). Following each interview, transcripts were coded line-by-line to allow the researcher to begin viewing the data analytically and render some codes into categories (Charmaz, 1990). The sets of codes resulting from this process were then compared, allowing for identification of common ideas and themes inviting further investigation. These themes refined the focus of the subsequent interviews. To facilitate reflection, field notes were made after each interview and memos made throughout the research process, recording observations about process, content and emerging themes. The process of raising themes to categories was facilitated by a process of constant comparison of the data. Through this continuing process, higher level analytical categories were generated. The use of QSR International's NVivo 9 qualitative data analysis software enabled data and analytic codes to be more easily managed. Having identified a category or link between categories, the researcher actively looked for 'negative cases', i.e. instances that did not 'fit', with the aim of arriving at an inclusive account of participants' experiences and adding depth

and density to the emerging theory (Willig, 2008).

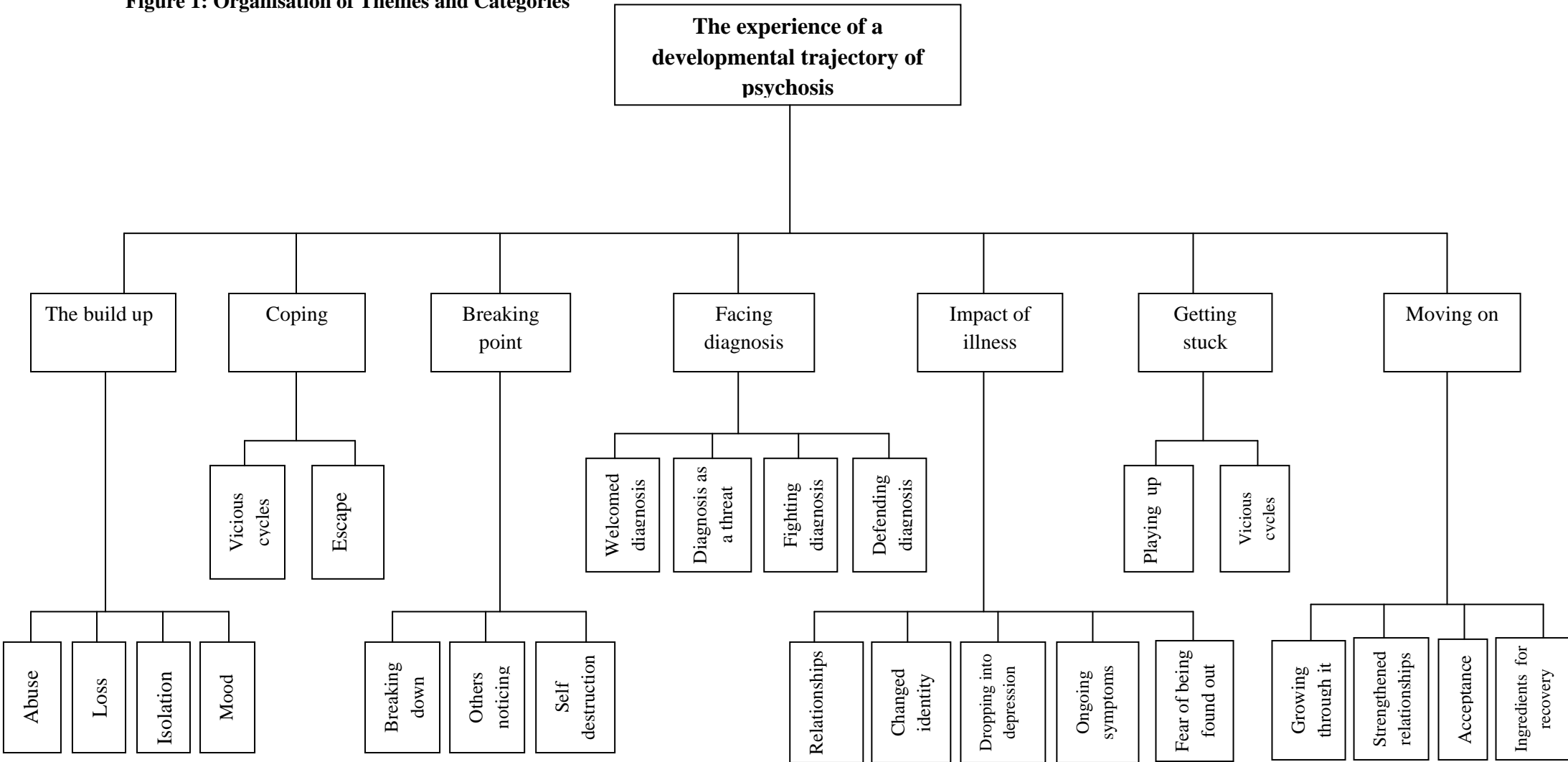
This process of refining themes and categories was continued until the researcher considered that ‘theoretical sufficiency’ has been achieved. This was in line with the definition outlined by Dey (1999, p. 117): “the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications”.

7.4. Results

7.4.1. Key categories

Seven key categories emerged, describing what the author observed as being developmental trajectory (stages) of young people experiencing and adapting to psychosis. The main analysis was structured in a sequential fashion as that reflected how the narratives unfolded. The key categories and the sub-categories contained within them are depicted in Figure 1. The overarching theme (core category) was one of *the experience of a developmental trajectory of psychosis*. Within this, participants spoke about their experiences in terms of seven broad categories: *the build up, coping, breaking point, facing diagnosis, impact of illness, getting stuck and moving on*.

Figure 1: Organisation of Themes and Categories



7.4.2. Grounded theory

Space does not permit an examination of the key categories and subcategories. Instead, this paper will focus on the core psychological processes that emerged as underpinning each of these stages. The model in Figure 2 represents a grounded theory of the experience of and relationship between psychosis, depression and anxiety. It illustrates the links between some of the key concepts and processes which emerged from the interviews and elucidates the processes that may be involved in young people's experience of psychosis and affective disturbance. As such, it can be considered a process model. As a caveat, it should be noted that the proposed model has emerged through the researcher's interpretation of participants' accounts of experiences of psychosis and is, therefore, tentative; requiring further research to validate the proposed processes:

During the onset of psychosis, in making attempts to cope with changes to their mood and developing psychotic phenomena, young people get stuck in vicious cycles of behaviour which lead them to become isolated from others and cope alone with these experiences [1]. These vicious cycles are motivated by fear of consequences (hospitalisation, medication), mistrust of others and fear of anticipated rejection. In addition, they frequently make attempts to escape from these experiences through self isolation, the use of drugs, truanting, self harm and suicide attempts [2].

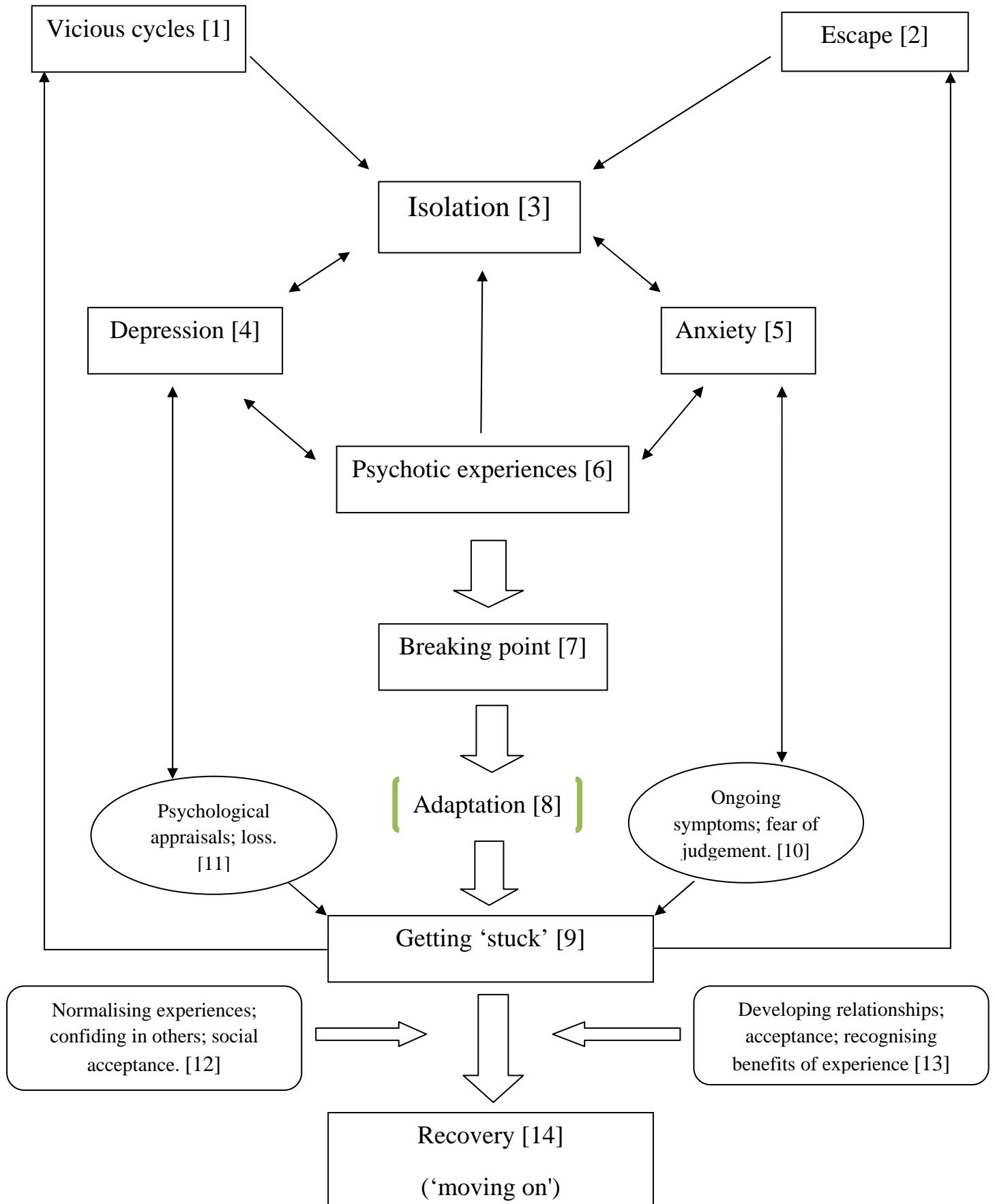
These processes of maladaptive coping and poor mood regulation lead to increasing isolation [3], which is then linked to the development of depression [4] and social anxiety [5], both of which aid the development of psychosis. The more isolated, depressed and anxious the young person feels, the more omnipotent and distressing the hallucinatory experiences and delusional beliefs become [6] and the more anxious and low they feel.

At some point, young people are no longer able to contain their experiences and they reach 'breaking point' [7]. At this stage, help is mobilised, either because the young person makes a suicide attempt, breaks down and discloses their experiences to someone, or their psychotic symptoms become obvious to others. The young person then faces the task of adaptation [8], whereby the same patterns of maladaptive coping (escape and vicious cycles) open up, functionally 'trapping' the young person [9] and hindering adaptation to the experience. The experience of continued psychotic symptoms in some young people elicits feelings of depression and anxiety, as does the fear of their illness being 'found out' by others [10]. In

addition, during this process, young people evaluate the impact of the illness on their life and experience feelings of loss (of hope, control, identity, aspired future self, friendships) and perceived and actual stigma, which further contribute to experiences of low mood and anxiety [11].

Several experiences facilitate a young person to begin moving on from this 'trapped' position. Experiences of normalisation, through contact with a service or meeting other people with similar problems, confiding in others and experiencing social acceptance of their diagnosis/ difficulties are key [12]. Likewise, developing new relationships, beginning a process of acceptance of what the experiences have entailed and, latterly, recognising any benefits that have emerged as a result of the experience [13] contribute to the process of recovery [14].

Figure 2: A grounded theory of the experience of depression and anxiety in adolescents developing psychosis



7.5. Preliminary hypotheses

The findings from this study suggest that depression and anxiety are not co-morbid features of psychosis, but are intrinsically linked to the underlying processes involved in coping with and adapting to psychosis. Maladaptive coping and mood regulation strategies are represented throughout this process and it is these that appear to be linked to the manifestation of depression and anxiety, partly mediated by isolation. This is demonstrated by the fact that these processes are active in the onset and origin of psychosis, as well as the adaptation to psychosis and recovery stage.

7.6. Discussion

7.6.1. Integration of findings with existing literature

In keeping with current literature (Iqbal *et al.*, 2000; Birchwood *et al.*, 2006), social anxiety and in particular, depression, were highly prevalent in the experiences of these young people. A concerning finding was the frequency of suicidal ideation and intent experienced by these young people. Five of the participants had made at least one attempt to end their life, four had made several attempts. The remaining participant spoke about experiencing suicidal ideation following relapse but she had not made an attempt to end her life. Whilst acknowledging that the limited sample in this study may not be reflective of the population, this finding suggests an alarming prevalence of suicidal behaviour, which appears to exceed that of recent existing studies. For example, Falcone *et al.*, (2010) report a 32 per cent incidence of suicide attempts in this cohort and, in keeping with the current study, found that depressive symptoms were significantly correlated with increased suicide attempts.

Arguably the most consistent theme to emerge from participants' narratives was *isolation*. What was striking was how many of the experiences narrated by participants led to them become isolated, and how isolation was experienced as linked to depression, anxiety and psychotic symptoms. Isolation has long been recognised as a risk factor for the development of psychotic illness (Kohn & Klausen, 1955). Young people with psychosis tend to have significantly smaller social networks, with fewer friends, fewer people to whom they can turn in a crisis and limited romantic relationships (Macdonald *et al.*, 2000). What was interesting about these findings was that, whilst this was true of some participants, others described having a good network of friends prior to the onset of psychosis but choosing to engage with them less as their problems developed. For them, isolation did not stem from limited

opportunities for social interaction or from anxiety about being around others, at least initially. Rather, they described something *functional* for them about stepping back from others, e.g. 'Being alone helps me to cope with difficult feelings'... 'means that I won't worry anyone'... 'helps me to feel safer', etc.

Whilst isolation is a well observed factor for individuals during the prodrome, it is important to note that in this group of young people, these same vicious cycles that had been present during the prodrome (e.g. choosing not to disclose their experiences, self isolating, drug use,) also occurred during the adaptation phase, contributing to a sense of 'getting stuck' in psychosis. Essentially, these similar cycles contributed to a failure to adapt to the experience for many. These findings link in to research by Garety *et al.*, (2001) who purport that social isolation provides a facilitative environment for the development and maintenance of delusional ideas. One hypothesised pathway is that social isolation facilitates more ready acceptance of the psychotic appraisal by reducing access to alternative, more normalising explanations (White *et al.*, 2000).

The theme of escape was common in most participants' experience. Young people clearly described using drugs as a means of escaping what they perceived to be unbearable emotions (e.g. grief, anxiety), in addition to escaping the experience of psychotic phenomena. The findings relating to coping have potential relevance to several areas of literature. Firstly, the concept of 'recovery style' (McGlashan, *et al.*, 1977), and the related notion of a 'sealing over' coping style, whereby a person copes by minimising the significance of symptoms and the impact of psychosis on their life, and by taking a disinterested stance towards the experience. An 'integration' coping style, by contrast, describes a process whereby a person acknowledges the importance of their psychosis, bears its painful aspects, is curious about it and relinquishes their attempt to "go it alone" (McGlashan *et al.*, 1975). A young person using escape as a means of coping indicates that they may be attempting to 'seal over' their experience.

Birchwood *et al.*, (1993) conceptualise psychotic illness as an apparently uncontrollable life event, and propose that depression following psychosis arises due to psychological appraisals about the illness, particularly relating to beliefs about lack of control over the illness ('entrapment') and appraisals of loss of autonomy and social role (Rooke & Birchwood, 1998). The findings from the current study would support these hypotheses. Several participants spoke about their experience of 'dropping into depression'; something which was

experienced as directly related to specific psychological appraisals about the meaning or significance of their psychotic experiences. These appraisals included: loss of hope for the future; loss of control over life, and; a sense of having missed out on ‘normal’ life and experience. The current findings also add to these hypotheses, by highlighting appraisals about loss of identity as another potential mediator between psychosis and depression.

What was particularly striking about these findings was the clear description of reciprocity between low mood, anxiety, isolation and psychotic experiences. This relationship appears to be central to the young person experiencing psychosis, and to the failure to adapt and recover from psychosis in some cases. Most participants reported a bi-directional relationship between their experience of psychotic symptoms and low mood. These findings are in keeping with current literature. Smith *et al.*, (2006) found that individuals with lower mood and lower self esteem have auditory hallucinations of greater severity and more intensely negative content and are more distressed by them. The findings from this study provide support for their hypothesis that the direction of the relationship between auditory hallucinations and low mood is driven both by the voices and the negative affect that results.

7.6.2. Clinical implications

What emerged as key in this study was young people’s experience of psychosis as one which was intrinsically experienced and described in relation to others. The findings support a psycho-developmental account, which implies that therapeutic priority should be given to re-establishing the young person’s links with their peer group, through strategies such as work placement schemes, peer group activities, etc (Harrop, 2002). Young people’s experience of social acceptance appeared to be ‘corrective’, i.e. a factor which facilitated them beginning to recover.

The current findings raise the interesting question of how useful the clinical labels ‘depression’ and ‘social anxiety’ are in this particular context. Whilst the psychological literature focuses on these two terms, used to denote specific kinds of *experiences*, it could be argued that their use in this context deflects attention from the *processes* which contribute to their development. It could be argued that substituting these terms with ‘emotions/ beliefs/ behaviours that lead to isolation’, may be more useful (and perhaps more normalising) in terms of understanding these processes and working therapeutically to reduce them.

Research indicates that individuals who have onset of psychosis in adolescence tend to have significantly longer duration of untreated psychosis (DUP) (Ballageer *et al.*, 2005). What the current findings indicate the *reasons* why young people are actively avoiding help seeking at this point, i.e. fear of hospitalisation and/ or medication and concern about having a label attached to them. The commonality of these experiences in the current findings indicate strongly that young people are not receiving normalising information about psychosis and that societal stigma about the illness prevails. Services need to give young people ‘permission’ to disclose their experiences. At a wider level, young people would benefit from high profile national educational campaigns about psychosis, clearly communicating the message that we understand reasons why young people are fearful to access services but that the sooner they receive support the easier things will become. Considering the detrimental impact that choosing to cope alone has on young people’s mental health and the related risk of suicide, efforts to remedy this on a national level should be a priority.

7.6.3. Limitations of the study

Given the constraints posed by limited time and resources, the current study has some methodological and conceptual limitations. Firstly, the scale of this research did not allow for full realization of the concepts of theoretical sampling and sufficiency. It is likely that further interviews would have led to further refinement of categories and subcategories and possible that new categories may have emerged from this process. Secondly, it is possible that the sampling method may have introduced an element of bias, as those participants who were invited to take part but declined may have differed in important characteristics from those who participated.

7.6.4. Future research

In terms of the current findings, an interesting area for future research might be on the experience of ‘moving on’, in particular, an exploration of what contributes to the apparent shift in young people’s appraisals between the ‘getting stuck’ and ‘moving on’ stages, whereby appraisals change from those of loss, shame, etc. to perceived benefits of the experience.

An interesting area for future research would be to consider the current findings in light of attachment theory (Bowlby, 1969), which has been used as a framework to explain the link

between emotional distress and help-seeking, or lack thereof (Gumley & Schwannauer, 2006).

7.6.5. Summary and conclusions

The overarching theme to emerge was that of the experience of a developmental trajectory of psychosis. In line with current literature, findings indicated that depression, social anxiety and suicidal behaviour are common among young people who have experienced a first episode of psychosis. These experiences appear to be intrinsically linked to underlying processes related to coping and adaptation to psychosis, rather than representing ‘true’ co-morbidity. Isolation, low mood and anxiety were universal outcomes and appeared to be mediated by maladaptive forms of coping and mood regulation (vicious cycles and attempts to escape) in addition to psychological appraisals and negative experiences related to the illness (e.g. stigma and loss of relationships). These processes occurred during the pre-psychotic stage as well as the adaptation and recovery phases. These findings strongly suggests reciprocity in the relationship between isolation, depression, anxiety and psychosis, shedding further light on why some people fail to adapt to and recover from psychotic illness. However, further research is needed to develop these findings. Given the evidence on outcome and risk of suicide for young people with adolescent onset psychosis, research in this area should be a priority.

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9. Appendixes

Appendix 1: Submission guidelines for journal article and systematic review.

Appendix 2: STROBE guidelines for systematic review

Appendix 3: Research ethics approval documentation.

Appendix 4: Participant information sheet.

Appendix 5: Participant consent form.

Appendix 6: Examples of researcher memos.

Appendix 7: Examples of researcher diagrams.

9.1 Appendix 1: Author guidelines for article submission (Schizophrenia Bulletin).

9.2. Appendix 2: STROBE guidelines for systematic review

9.3. Appendix 3: Research ethics approval documentation.

9.4. Appendix 4: Participant information sheet.

9.5. Appendix 5: Participant consent form.

9.6. Appendix 6: Examples of researcher memos.

9.7. Appendix 7: Examples of researcher diagrams.